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A Qualitative Analysis of the Barriers Faced by Nursing Assistants and Medication Aides in the Care of Dysphagia Residents

Lauren Kreuzberg
University of Nebraska - Lincoln

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Lauren Kreuzberg

Bachelor of Science, Nutrition Science

College of Education and Human Sciences

University of Nebraska-Lincoln

Bachelor of Science, Gerontology

College of Public Affairs and Community Service

University of Nebraska-Omaha

Faculty Mentor: Julie Masters, PhD, Gerontology

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Abstract

Dysphagia refers to the symptom of difficulty in swallowing that accompanies several prevalent conditions in the older adult population, including amyotrophic lateral sclerosis (ALS, Lou Gehrig's Disease), stroke, Parkinson's Disease, Multiple Sclerosis, dementia, various cancers, and brain tumors (Allari, 2014). Many older adults who suffer from these conditions reside in nursing facilities, where most of their care is provided by certified nursing assistants (CNAs) and medication aides (MAs). However, the extent of these workers' knowledge and competence in providing care to nursing home residents with dysphagia is vastly unresearched. The qualitative analysis investigates themes among interviews with fifteen CNAs and MAs regarding their experiences and perceived barriers caring for residents with dysphagia. The participants identified barriers to providing excellent dysphagia care including low staff to resident ratio, lack of proper education, and dietary issues. The responses show the need for dysphagia care education in the formal CNA and MA training and during on-the-job training. Though additional research is needed, there seems to be an immediate need for intervention in educating frontline workers about how to care for residents with dysphagia in a safe, dignified manner.

Key words: Dysphagia, CNA training, medication aide, certified nursing assistant, CNA, swallowing difficulty, gerontology

Introduction

The population of older adults worldwide is growing at an unprecedented rate. The baby boomer generation in the United States is growing older. By 2029, all baby boomers will be 65 and older (United States Census Bureau, 2018). With age often comes health issues. Older adults are many times overlooked and negatively stereotyped, and devalued. In reality, they are people the same as everyone else, deserving of equal opportunities for quality care and appreciation. This being said, older adults are vulnerable to abuse, neglect, and exclusion, as age discrimination is very prevalent. One issue that comes with aging as seen in older adults in their homes, skilled nursing facilities, and rehab settings is dysphagia. Dysphagia refers to difficulty swallowing that can lead to dehydration or malnutrition, aspiration pneumonia or even death (Garcia & Chambers, 2010). Dysphagia is a symptom that accompanies many different illnesses and diseases, including strokes, various cancers, traumatic brain injuries, Parkinson's Disease, Amyotrophic Lateral Sclerosis, and more (Garcia & Chambers, 2010). Because chronic health problems are prevalent in older adults, dysphagia is common among this population (Garcia & Chambers, 2010). The issue of keeping food and meals enjoyable and socially, emotionally, and physically fulfilling with modified diets and artificial nutrition and hydration is vastly under researched. Dysphagia diets including modified diets, pureed foods, thickened liquids, artificial nutrition and hydration (ANH), are known to increase length and quality of life, but there are many costs as well. It is likely to impact self-esteem, enjoyment of meals, social experiences, and cultural identity. When someone loses the ability to swallow regularly, their personal value does not decline. It is imperative to work to enhance or maintain dignity, self-worth, and life satisfaction of dysphagic residents receiving artificial nutrition and hydration. With 77 million people aged 60 and older by the year 2020, it is essential that this problem is addressed and

something is done for our grandparents, mothers, fathers, siblings, and loved ones (United States Census Bureau, 2018).

Through my own experiences working in nursing facilities, I saw the various shortcomings of our senior care firsthand. With my two majors of nutrition science and gerontology, I was naturally inclined to investigate this topic to find ways we can treat our older adults with greater dignity and care. There are few aspects of life that nutrition does not affect, and dysphagia is a popular symptom of nursing home residents that can take a large toll on quality of life. I wanted to see if other nursing assistants and medication aides shared similar experiences to me to find out how well dysphagia is managed in nursing homes. Through interviewing certified nursing assistants and medication aides, I was able to identify shared barriers faced in providing dysphagia care and make possible suggestions for what changes can be made.

Literature Review

Dysphagia

Dysphagia is a serious symptom of many diseases with various causes and impacts. Dysphagia can result from a failure of the sensory or motor mechanisms that are designed to regularly transport a bolus through the mouth, pharynx, and esophagus (Garcia & Chambers, 2010). Places where issues causing dysphagia may occur include chewing food into a bolus, soft palate retraction and elevation blocking the nasal cavity, hyoid bone and laryngeal elevation to relax the pharynx for food to enter, epiglottis closure to protect the airway, contraction of pharyngeal sphincters, opening of the upper esophageal sphincter to allow food into the esophagus, and finally propulsion into the stomach (Garcia & Chambers, 2010). Pocketing food in the sides of the mouth, drooling, and coughing can be indicators of possible dysphagia (Garcia & Chambers, 2010). However, nearly 55% of patients who aspirate do not show any symptoms, no coughing or struggling (Garcia & Chambers, 2010).

Complications of Dysphagia

In a study completed in continuing care facilities, 72% of patients who had aspiration pneumonia had a neurologic disease resulting in dysphagia, and 24% of all the patients with aspiration pneumonia died (Garcia & Chambers, 2010). Hospital patients with dysphagia, on average, stay longer than non-dysphagia patients and are more often discharged for admission into a nursing facility (Garcia & Chambers, 2010). Sadly, however, the implications of dysphagia are not just physical. A study of dysphagia patients found that 55% of participants thought their dysphagia made life less enjoyable, 41% reported anxiety and panic during mealtimes, 36% avoided eating around others due to their dysphagia, 50% reported eating less, and 33% stop eating when they are still hungry (Garcia & Chambers, 2010).

Dysphagia Management

Dietary modifications, including changing consistency foods or liquids, are key to the dysphagia management plan (Garcia & Chambers, 2010). A multidisciplinary team is best equipped to manage dysphagia, as different specialties can bring varying skills and knowledge to the care team. It is estimated that 31%-48% of nursing home residents receive modified solid foods (Garcia & Chambers, 2010). A level one dysphagia diet (pureed) is accommodated for those with severe swallowing problems, levels two (mechanically altered) and three (advanced) accommodate those with some ability to chew, and level four (regular) is for those on unrestricted, regular diets (Garcia & Chambers, 2010). Thin liquids such as regular water, milk, coffee, and so on can impose risks upon those with dysphagia, a thickening substance is added to adjust the thickness to match the resident's swallowing ability (Garcia & Chambers, 2010). Different thickness levels include nectar-like, honey-like, and spoon thick, increasing in viscosity (Garcia & Chambers, 2010). It is also essential for high quality care that residents on restricted diets are being reevaluated to monitor for needed changes in diet, whether it becomes more or less restrictive (Garcia & Chambers, 2010).

The Need for Artificial Nutrition and Hydration

As various diseases and cancers progress, many residents start to lose the ability to swallow, a condition referred to as advanced dysphagia. With this, they are unable to eat and drink, so artificial nutrition and hydration become necessary. When residents decline to levels where artificial feeding is necessary, a unique issue that arises for the resident, caregivers, family, and medical team is how to maintain the dignity of the resident, even with thickened liquids, pureed diets, and tube or intravenous feeding. For many, this news is a lot to consider and is an intimidating step in their journey to the end of their life.

There are various reasons why feeding tubes and thickened liquids become necessary. Some residents do not eat as much due to increased severity of symptom expression, while others decline to eat as a way to control one aspect of their condition (Gillespie & Raftery, 2018). Symptoms can interfere with appetite or impair the body's use of nutrients from the diet (Gillespie & Raftery, 2018). In cases of amyotrophic lateral sclerosis (ALS, Lou Gehrig's Disease), stroke, Parkinson's Disease, Multiple Sclerosis, dementia, various cancers, and brain tumors, the difficulty lies in the physical act of swallowing, dysphagia (Allari, 2014).

I. Dementia

Dementia is chronic and progressive. One of the specific common issues sufferers face is dysphagia in the end-of-life stages (Teno, 2009). Dysphagia leads to weight loss and higher risk of aspiration, chest infections, and recurrent pneumonias (Teno, 2009). Those with dementia and dysphagia are more likely to aspirate, and have double the chance of dying from aspiration pneumonia (Payne & Morley, 2018). Those with dementia are more likely to refuse meals, become distracted, or not be able to recognize their hunger (Payne & Morley, 2018). Oftentimes, dysphagia in residents with dementia is not recognized (Payne & Morley, 2018). Dysphagia precedes serious complications, including weight loss, aspirations, malnutrition, and dehydration (Payne & Morley, 2018). Thickening liquids, modifying foods, limiting distraction and background noise, and following a routine have been shown to help demented residents with dysphagia (Payne & Morley, 2018). According to research by Teno, feeding tube insertion in end-stage dementia residents in nursing homes is found in areas where transitions in health care are more common. These transitions in health care refer to moves from nursing homes to hospitals, back to nursing homes, to rehabilitation, and so on (2009). It is likely these healthcare transfers are poorly executed (Teno, 2009). They can lead to medical errors such as advance

directives not being accurately passed on or passed inaccurately to different facilities along with functional decline in residents (Teno, 2009). Understandably, these poor transitions can also lead bereaved families to mistrust the medical team or not believe everything possible was done for their loved one (Teno, 2009). Physicians need to be aware of the dysphagic effects of diseases and their treatments in order to provide the best care for each individual resident (Brady et al., 2017).

II. Cancer

Further, a massive 63% of cancer patients experience swallowing difficulties in their last year of life (Brady et al., 2017). This can be a consequence of direct tumor invasion, comorbid conditions, and cancer treatments. If the dysphagia is treatment related, it is often a result of radiation induced esophagitis and oral mucositis (Brady et al., 2017). Brady explains direct tumor invasion complications by stating, “Direct tumor invasion may result in recurrent laryngeal nerve compression causing unilateral vocal cord palsy, increasing risk of swallowing issues due to reduced airway protection” (2017). Also, esophageal compression or tracheoesophageal fistulas can occur in the esophagus (Brady et al., 2017).

Other symptoms that relate to the ability to eat that have been reported by advanced cancer patients include loss of appetite, reported by up to 86% of patients, weakness by 60-74%, nausea from 17-31%, dry mouth from 34-40%, taste changes from 22%, and weight loss ranging from 46-86% (Acreman, 2013). Parts of chemotherapy cause decreased appetite, therefore worsening nutrition in patients. This triggers worse wound healing ability, lower immune response, less effective muscle maintenance and development, decreased respiratory drive, and reduced cardiac output due to cardiac atrophy (Gillespie & Raftery, 2018). Also, mental functioning is impaired when suffering malnutrition. An alarming statistic presented by Brady

explains that the number of worldwide cancer cases is set to increase by 75% in the next twenty years, so dealing with dignity in the use of artificial nutrition is extremely important (2017).

Cancer affects not only the physical ability of the patient but also the digestive ability. According to Acreman, cancer alters glucose metabolism, increases rate of glucose oxidation, and increases the rate of protein metabolism. It also decreases protein synthesis but increases its breakdown and alters lipid metabolism (2013). Aside from cancer, other terminal illness also alters nutritional status by reduction of gastrointestinal absorption and increase in nutrient requirement from physiological, metabolic, and anatomical changes such as malabsorption, cachexia, and increasing tumor mass (Acreman, 2013). The process of dying reduces bodily functions, decreasing hunger (Acreman, 2013). More reasons artificial nutrition become necessary are the side effects from medicines, usually narcotics or opioids, often given in end-of-life stages, including effects of nausea, vomiting, diarrhea, and constipation (Acreman, 2013). Emotionally, the challenges patients face during this time can also reduce appetite.

Artificial Nutrition and Hydration Options

When it comes to artificial nutrition and hydration, there are several different techniques to be aware of. As defined by Marcolini et al., artificial nutrition and hydration is "a group of medical treatments provided to patients who cannot meet their daily requirements orally, with resultant malnutrition, electrolyte abnormalities, and/or metabolic derangements" (2018) This nutrition can be administered to the patient in need through a tube inserted into the GI tract, called enteral, or through a catheter into the venous system, called parenteral (Gillespie & Raftery, 2018).

I. Enteral Tube Feeding

For a patient with dysphagia or other medical issues preventing them from being able to eat, but still have a functioning gastrointestinal tract, enteral is the treatment of choice (Gillespie & Raftery, 2018). Enteral tube feeding into the GI tract has better clinical outcomes, showing lower rates of sepsis. Enteral options vary from nasogastric, also known as an NG tube, or nasoduodenal tubes, which enter through the nostril, when the patient is not expected to need the tube feeding for longer duration than just six weeks (Gillespie & Raftery, 2018). For longer term need, the patient would typically require either a surgically placed percutaneous endoscopic gastrostomy, gastrojejunostomy, or a jejunostomy (Gillespie & Raftery, 2018). The gastrostomy is commonly referred to as a "G-tube", whereas the jejunostomy is shortened to "J-tube" (Allari, 2014). The different terms refer to the area of the stomach or intestine the tube is inserted into, gastrostomy referring to the stomach and jejunostomy referring to the jejunum of the small intestine. As enteral feeding is fit for patients who have lost the ability to swallow, these patients are commonly suffering from cardiovascular accident/stroke, multiple sclerosis, Parkinson's, and dementia, though stroke is the most common (Gillespie & Raftery, 2018).

II. Issues in Enteral Tube Feeding

Some issues with enteral tube feedings are the psychosocial consequences, such as negative feelings of frustration, anger, perceived alterations in their body image, and feelings of loss of control and independence (Gillespie & Raftery, 2018). These feelings of loss of independence are very common in older adults as they lose the independence to drive or stay in their home, so at the end of life, it is likely the patient has already struggled with some of these feelings. Another issue is sexual dysfunction or loss of libido. If someone does not feel attractive because they are tube fed, it will be hard for them to get in the mood for sex and pursue or continue sexual relationships (Gillespie & Raftery, 2018). This is also accompanied by

abdominal distension and diarrhea, which does not help the cause. All of these complicated emotions impact the patient's social life, continuing to their relationships with family members, friends, and loved ones (Gillespie & Raftery, 2018).

III. Parenteral Tube Feeding

However, when patients are severely malnourished, their gastrointestinal tract is injured or non-functional, or have severe intestinal failure, they would most likely use parenteral tube feeding (Gillespie & Raftery, 2018). This type of tube feeding involves the long-term placement of device placement into a large, often subclavian, vein (Gillespie & Raftery, 2018). This method is more expensive than enteral feeding and has adverse side effects. Some are due to injury to the thoracic duct, a subclavian hematoma, contamination, and trace element deficiencies. Some positive sides, though, are that the patient can receive this artificial nutrition at home when the need is long-term (Gillespie & Raftery, 2018). Patients suffering from Crohn's disease, malignancy, gastrointestinal disorders, and vascular disease are more likely to require parenteral feeding (Gillespie & Raftery, 2018). Enteral feeding brings on many of the same psychological issues as parenteral.

IV. Thickened Liquids

When patients can still swallow and are not to the point of needing tube feeding, thickened liquids are implemented. This is a common practice in skilled nursing facilities as thirty to ninety percent of residents show some difficulty in chewing or swallowing (Castellanos, Butler, Gluch, & Burke, 2004). Dysphagic patients are at increased risk for dehydration and aspiration pneumonia, so providing thickened liquids to these patients allow them to use their abilities while they still have them, as well as enjoy the taste of the food to stimulate their senses (Castellanos et al., 2004). Consumption of thickened liquids is useful in avoiding aspiration

pneumonia and preventing dehydration. The most common thicknesses offered are nectar-like, honey-like, and pudding/spoon thick (Castellanos, 2014). The varying thicknesses accommodate varying swallowing abilities and different aspiration risk statuses. Even though there is an estimated thirty to ninety percent of skilled nursing facility residents with dysphagia, Castellano's study showed that on average, only 8.3% of residents were receiving thickened liquids, mostly nectar consistency (2004).

Family Relationships and ANH

Another way the need for tube feeding poses a threat to patients' dignity is the way food is used as a profession of love and care from family, friends, and loved ones. As food is a solid point of bonding, loved ones feel compelled to bring nice meals or snacks to share, trying to lift the patient's spirits as is often done between healthy individuals. However, when one cannot eat, the patient cannot accept the gift and only exacerbates negative feelings about oneself. Also, it can make the loved one feel helpless and struggle to come up with other ways they can bring some joy to their loved one. Often times, families are brought peace by believing that hydration decreases pain and replenishes the body, enhancing effectiveness of medications and making the patient feel better mentally and physically (Marcolini et al., 2018) The family may take on the role to maintain the patient's dignity and staying hydrated can help them feel accomplished in this goal (Marcolini et al., 2018). Sometimes, according to Marcolini, Putnam, & Aydin, "the family's insistence that the patient take nutrition may cause conflict even before the implementation [of artificial nutrition and hydration] becomes the only option. Strong beliefs in the value of nutrition and hydration at the end of life may give the family some satisfaction that they are helping the patient," while the consistent refusal by their loved one can exhaust feelings of helplessness in the family (2018).

What Acreman refers to as “aggressive feeding” takes place when the family encourages their loved one to eat when they have no desire to eat or will become sick if they do so, and has been noted in research of nutrition in palliative care (2013). It is crucial for health care providers to investigate positive ways to ensure that patients are not losing dignity with their dysphagia. As noted by Lee, Yang, & Ho, “poor chewing ability directly affects nutritional status and quality of life,” which is mostly a physical issue, yet psychological impairment is observed as well (2013).

Culture and ANH

A reason one may choose to forego ANH is cultural beliefs and values. In Western cultures, not eating parallels death, so artificial nutrition is used often. However, in Hindu traditions, the cessation of oral consumption signifies death but is not causal (Marcolini et al., 2018). The thought is that the person voluntarily ceases eating to maintain their dignity and independence through their death (Marcolini et al., 2018). Then, in Taiwanese culture, ANH is preferred because dying a hungry or malnourished death signifies that his or her soul will be restless after death, so utilizing the modified or artificial means is preferable (Marcolini et al., 2018).

Dignity and Dysphagia

Since the goal of health care is to enhance or maintain a high quality of life, artificial nutrition can be very helpful if it fits the residents’ desires. A major part in giving residents a high quality of life is maintaining their dignity. When someone has lost their dignity, their esteem drops and they inherently become less satisfied with the condition of their life. Since at the end of life, residents lose interest in eating, are fatigued, have a distorted self image, and are not as able to digest, it is common for the resident to suffer some psychological distress (Marcolini, Putnam, & Aydin, 2018). Troublesome dysphagic qualities include, but are not

limited to, having to clear the throat often, persistent coughing, the uncomfortable feeling of having food lodged in the throat, choking, and increased aspiration (Brady et al., 2017). Additionally, not being able to eat food that a patient desires may cause them feelings of isolation and disconnect (Gillespie & Raftery, 2018).

Artificial nutrition is used to ensure that nutrition is not a burden for the resident due to these symptoms, but rather enhances their quality of life by maintaining caloric and nutrient intake and energy, because malnourishment will only cause the resident to become more tired than they already likely are when fighting a chronic disease. Malnourishment and dehydration increase residents' susceptibility to low blood pressure, falls, pressure ulcers, infection, and organ failure (Murray, Miller, Doeltgen, & Scholten, 2013). According to Murray et al., following strokes, dehydration can "affect the ischaemic penumbra, induce neurological deterioration, influence the evolution of the stroke itself," and is strongly associated with increased risk of venous thromboembolism and stroke mortality (2013). Furthermore, dehydration has many negative effects on hospitalization rates, length of stay, and healthcare costs (Murray et al., 2013). Thickening liquids is effective in reducing aspirations in dysphagic residents, particularly those whose dysphagia is of neurological origin. This is because thickening them reduces their flow rates and makes it more cohesive and dense for the resident to ingest. It is easier to control while swallowing and prevents the liquid from spilling into the pharynx (Murray et al., 2013). It is easy to understand how thickening liquids prevents aspiration when imagining swallowing water versus swallowing honey or nectar.

One main reason that different methods of artificial nutrition and tube feeding have been developed and implemented is to help patients maintain nutrition, but an important issue that comes with this is the ability to enhance the quality of life, therefore aiding the patient in

maintaining their happiness and dignity. One can imagine the impact of receiving the news that they are no longer able to eat food and the stress this brings on. As Allari explains, artificial nutrition and hydration correct fluid and electrolyte imbalances to help the patient be more alert, have less nausea, prolong their life, improve their well-being and emotional support, and assure the patient and family that everything possible is being done to help them (2014). Artificial feeding helps alleviate the symptoms, reduces risk of complications, and without enteral feeding, those who are in need of it would die quickly due to malnutrition or aspiration pneumonia (Gillespie & Raftery, 2018).

Food and nutrition have varying particular importance from cultural reasons to religious, social, and psychological reasons (Allari, 2014). People have lifelong food habits linked to their backgrounds and childhoods, with fond memories attached to certain foods. With the memories come feelings of love, inclusion, friendship, health, and belonging (Gillespie & Raftery, 2018). When thinking of skilled nursing facilities, meal times may be close to the only time that residents socialize with someone not on the care team. It is often difficult to get residents engaged in activities to go to or difficult to transport them to the social events offered with the staff scheduled. Eating is associated with energy, health, and well-being (Allari, 2014). It is a regular part of life that most people are able to do for nearly their entire life, so losing this ability may easily make a patient feel like they are losing their independence. If they are not able to orally consume their food, they may think that modified or artificial nutrition and hydration will help them survive by providing them what they cannot give themselves anymore (Marcolini et al., 2018). However, with this, patients may also decide that having a gastrostomy or nasogastric tube is embarrassing, gross, or unattractive, worsening their quality of life. While the option is

open to decline this route if it is not curative, studies show that most will choose to implement ANH rather than forego the treatment (Marcolini et al., 2018).

However, in times near death, it is important to honor the patient's wishes to the best ability possible. For example, people may ask for a certain favorite food or meal from their culture, associated with happy, healthy times (Allari, 2014). At the very end, food is for happiness, not comfort or nutrition. The patient choice is the most important factor during this time (Allari, 2014).

Respecting Patient Choice

It is imperative for providers to respect the differences in decisions and rationale for choosing to use or forego ANH. These choices will differ between patients for widely varying reasons with different fears, symptoms, and experiences leading them to a certain thought process (Acreman, 2013). Using good listening skills can help medical staff uncover hidden reasons why a patient might fear using or not using ANH, so listening carefully and taking the patient seriously will help keep care individualized and most effective to that particular patient's needs (Acreman, 2013) The patient, caretakers, family, and health care teams should be communicating clearly, effectively, and completely about the benefits and risks, so each person in the process is involved and informed (Gillespie & Raftery, 2018) Delicate and thorough medical care is essential in maintaining the dignity of the patient by always keeping their best interest in mind and showing respect.

When it comes to medical treatment, the most important factor is keeping quality of life as high as possible (Lee, Yang, & Ho, 2013) Though artificial nutrition and hydration may not prolong life, it will optimize the patient's strength and enable them to enjoy the time they have remaining, to die with dignity and not of starvation, and retain some control over the process of

the disease (Acreman, 2013). As Marcolini et al. explain the role of the physician in this process, "treating a patient with ANH can be charged with emotional, social, and symbolic significance...can be anxiety provoking to all parties involved, providers must educate patients and their families about the risks and benefits involved…" (2018)

Action to Improve Quality of Life and Dignity

I. Person-Directed Care

Person-directed care is a change being made in nursing facilities to attempt to individualize care therefore enhance the quality of care being provided (Shune & Linville, 2019). Person-directed care during meal times includes increasing the patient choice, including where to sit, what to eat, what time, and so on, but also decreasing dining-related restrictions, and promoting positive social interactions (Shune & Linville, 2019). Though residents with dysphagia have added difficulties at meal times, like their non-dysphagia peers, individualization of care and social interaction are the most important psychosocial factors of quality of life at meal times (Shune & Linville, 2019). Residents' care should be individualized, not medicalized, and residents should be treated as individuals instead of their disease (Shune & Linville, 2019). Within dysphagia care, there are additional barriers in the empowerment of resident choice, as according to this study, a resident who has a pureed diet may just receive the food that is easiest to puree (Shune & Linville, 2019). The purpose of meal times can be easily overlooked in busy nursing facility staff agendas, but the purpose is not just to get nutrition, pills passed quickly, and getting the job done, but allowing the residents to experience the meal and the shared time with each other (Shune & Linville, 2019).

II. Role of Certified Nursing Aides and Medication Aides

Navigating the path of providing the highest quality of individualized care for residents with dysphagia without sacrificing their safety or increasing risks associated with dysphagia can be tricky, so having strongly trained, aware team members providing their care is essential (Shune & Linville, 2019). In this study, it was shown that when team members focused on the individualization of care, more successful dining experiences occurred (Shune & Linville, 2019). It is important for those who work regularly in nursing facilities, for example part time or full time, to put forth enough effort to know residents' food preferences to a certain degree (Shune & Linville, 2019). This takes increased effort and skilled communication, but goes a long way in the quality of care the residents receive (Shune & Linville, 2019). Plus, having thorough communication between all team members ensures any food restrictions, changes in diet, and preferences are followed (Shune & Linville, 2019). Also, residents prefer to choose where they sit and who they sit with, rather than being almost "assigned" a spot by their diagnosis (Shune & Linville, 2019). Residents and other employees can see when a worker is there for the paycheck and when someone truly cares about the residents (Shune & Linville, 2019). Having invested, communicative, caring team members consistently increased meal time experience for residents and job satisfaction for the employees (Shune & Linville, 2019).

While care team members have been established as important leaders of individualizing care, they cannot be expected to start a job flawlessly without proper training. More extensive training about dysphagia care is needed for those working in nursing facilities (Shune & Linville, 2019). Nursing aides generally feel underprepared for managing dysphagia and feel stressed while providing care (Chiang & Hwu, 2018). Various previous research shows CNAs and MAs may receive no formal training about dysphagia management and therefore lack confidence and skills when assessing, evaluating, and managing dysphagia (Chiang & Hwu, 2018). Continuing

education regarding dysphagia care is also rare, so the development of formal education and continuing education is severely lacking and severely necessary (Chiang & Hwu, 2018).

Even still, issues of regulations and finances further complicate the quality of care given, and as noted in this study, facilities are often under-resourced and there are not enough people to get the job done with empathy and quality (Shune & Linville, 2019). In this study, the majority of the staff verbally noted desiring to accomplish more than just the bare minimum at work, but felt more responsibilities were delegated at work without adding more resources (Shune & Linville, 2019). Since CNAs provide around 80% of care to residents, strong training and thorough guidance is essential in order to provide the highest quality of care possible to residents (Chiang & Hwu, 2018).

III. Nursing Staff and Liquid Options

Options are available to keep dysphagic patients nourished, but there are plenty of ways to increase quality of life for these people. As suggested by Murray et al., "Offering a greater amount of thickened liquids at mealtimes, when nursing staff are more available to assist individuals, may improve intake" (2013). If residents are left to consume thickened liquids at snack times or on their own, they are considerably less likely to drink the liquid and therefore become dehydrated (Murray et al., 2013). While thickened liquids are a good idea with great intentions, it often leads to dehydration as consumption is not adequately encouraged, monitored, assisted, and provided. In order for this to work, it needs to be provided and encouraged to maintain sufficient hydration and avoid the next step of tube feeding. Other ideas include providing more options for thickened liquids and more food options that have high water content and will help satisfy needs for hydration (Murray et al., 2013). It is imperative to consider and encourage thickened liquids and pureed diets because if a dysphagic patient can successfully

swallow modified food and liquid, they do not yet require enteral or parenteral feeding, and most would agree that thickened or pureed diets are better than receiving all nutrition through a tube.

IV. Essential Oils and Aromatherapy

An additional possibility to help with patient nutrition by artificial means could benefit from the use of essential oils. As many medications that geriatric patients ingest can diminish appetite, the scent of black pepper is an appetite stimulant, which would cause a patient to have the desire to eat and drink when they normally might not (Geiger, 2017). As Geiger explains, "In older patients in this Japanese study of carefully selected patients suffering from stroke with swallowing dysfunction, black pepper essential oils inhalation resulted in improvement of reflexive swallowing movement regardless of level of consciousness or physical or mental activity, possibly by activation of the insula and orbitofrontal cortex" (2017). Further, the immune system can be strengthened by inhalation of eucalyptus essential oils (Geiger, 2017).

Reported by Blissett, Chima, and Lantz, from a study utilizing essential oils in adults ages 55-99, over 90% reported feeling "very satisfied" after utilizing aromas (2018). They used individualized aromatherapy for patients, and the results showed an increase in satisfaction with healthcare, greater feelings of well being during use and increased engagement with healthcare providers and in activities (Blissett et al., 2018). The use of aromas is empowering for patients and "offer amazing opportunities in settings where patients often feel ignored, such as hospital hallways and outpatient waiting areas" (Blissett et al., 2018). If the use of aromatherapy and essential oils is able to boost appetite and immune function, as well as increase sense of care satisfaction and well-being, there is exponential potential for growth in care plans. Implementing aromatherapy to replenish their impoverished sense of taste in the form of smell has the potential to improve care of dysphagic patients drastically. Most importantly, the better a patient feels, the

better they feel about themselves, the higher their confidence, the more fulfilling and enjoyable, happy life they are able to live.

V. Emphasis of Patient Happiness

More ways to help maintain the dignity of patients who are receiving artificial nutrition and hydration include showing consistent support of the patient's decisions and not treating them differently while they are being tube fed or consuming modified food or drink such as pureed meals or thickened liquids. Family members and loved ones should not eat around the patient or bring them food that they cannot eat if it will make the patient feel sad and excluded. Keeping the situation as normal as possible will help the patient feel normal themselves as they navigate a new journey that brings on many unpleasant feelings. The patient's health and well-being is of the utmost importance, not appearance or lack of ability to eat. Emphasizing health and happiness will encourage the vulnerable patient to not feel shame in their tubes. Cultural decisions need to be respected by all involved. If a patient's beliefs differ from those of a loved one or medical staff, it is best for the loved one and imperative for medical staff to support the decision of the patient and value their beliefs, especially at the end-of-life.

Conclusion

All in all, there are many options available for dysphagic patients. The massive number of older adults in our world is growing rapidly and dysphagia is going to become an even more prevalent issue. It is imperative that we find ways to implement artificial nutrition in ways that keep the patient happy and maintain their dignity. Conducting research in life satisfaction and nutrition in dysphagic patients using ANH is essential for progress to be made in this field. This is one way we can better prepare to take loving care of our elders as more people rise in age.

As mentioned, there are options such as thickened liquids, enteral, or parenteral tube feeding. Thickened liquids allow patients to continue using their swallowing ability and taste the liquid they are consuming. However, without adequate supervision and monitoring of intake, it is easy for patients to become dehydrated, and in this case, tube feedings would be better to ensure that the patient's nutrient and fluid intake is sufficient. There are measures that can be taken to increase the likelihood of patients receiving thickened liquids or pureed diets are indeed getting proper nutrition and hydration such as providing plenty of different options for foods and fluids for the patient, encouragement from the medical team and family, as well as assisting the patient eat or drink. Tube feedings are successful in providing adequate or above adequate nutrition and hydration to patients, but they are then no longer able to taste their food and drink. Some cultures do not support tube feeding, and patients are likely to lose some life satisfaction when they must be fed through a tube in their stomach. Ultimately, if tube feeding is not curative, it can be denied by the patient. Healthcare teams need to take the steps to ensure that patients are receiving the best possible care for them, which could be thickened liquids, pureed meals, enteral or parenteral tube feedings, or no artificial means at all. Our population is growing older and issues of artificial nutrition and hydration in dysphagia patients will be growing too. We have to be prepared.

Methods

Qualitative research gives participants freedom in their responses to report their firsthand experiences and thoughts. They are not limited by a scale or answer options. The open-ended nature of qualitative interviews allows great detail and specific events to be shared. This study consisted of twelve interview questions and fifteen interviewees. There were three demographic questions and nine experience based questions.

Participants

Participants' experience working as a CNA or MA ranged from six months to six years, with an average experience time of 2.52 years. Seven participants worked in long term care, three in rehabilitation, two in a hospital, two in memory care, and one in home health care. One participant completed the formal certification class in 2014, five in 2015, two in 2016, three in 2017, and four in 2018.

Recruitment

A snowball sampling technique was implemented to recruit participants. Known eligible participants were recruited, then asked about other eligible participants who may be willing to participate. This was done until the sample size of fifteen was met.

Interview procedures

Interview times were set up via email. Invitations to participate were sent first. If the participant indicated they were willing to take part in the study, a time and meeting location was set, and the consent form was attached for preview. Interviews took place in private rooms on the University

of Nebraska-Lincoln campus or at the workplace of the individual. After consent was obtained verbally, the consent form was signed by the participant. Upon the beginning of the interview, a recording began. The recording ended at the end of the interview. After transcription and analysis of answers, recordings were destroyed.

Data collection

Interviews were recorded once consent was obtained. Recordings were transcribed for analysis and deleted post-transcription. Transcriptions are in a locked folder on a password protected laptop.

Data analysis

The interviews were transcribed for analysis. Answers were organized by question to find themes. Answers from different participants who had similar experiences and outlooks were grouped together into categories. This process was done for all twelve questions.

Ethical standards

Approval for this research study was given by the University of Nebraska-Lincoln Institutional Review Board. Primary investigator Lauren Kreuzberg and secondary investigator Julie Masters, PhD., are both up-to-date on the IRB certifications. The research was marked exempt category 2a on July 17, 2019.

Results

Overall Results

Fifteen participants were interviewed. The average years of experience working as an aide was 2.52 years (SD=1.514). Experience ranged from six months to six years. One participant (6.67%) had less than one year of experience working as an aide. Five participants (33.33%) had one to two years of experience. Two participants (13.33%) had two years of experience. Three (20%) had three years of experience and three (20%) had four years of experience. One (6.67%) had greater than 5 years of experience, reporting 6 years. Twelve participants had certified nursing assistant (CNA) experience only, and three participants had experience working as a medication aide and CNA.

Three participants (20%) reported their experiences working in rehabilitation. Two (13.33%) reported hospital-based experiences, and two (13.33%) reported memory care facility-based experiences. Seven (46.67%) reported their experiences from working in long-term care. One participant (6.67%) reported from experience in home health. The majority setting was long-term care.

Length of time since formal training ranged from one to five years, ranging from 2014-2019. One participant (6.67%) received their training in 2014, five (33.33%) in 2015, two (13.33%) in 2016, three (20%) in 2017, and four (26.67%) in 2018.

Years of Experience	Years
Mean	2.52
Range	6 months to 6 years

Qualitative Results

Question 4: Tell me about your experiences providing care to dysphagia patients.

For this question, only two of fifteen participants (13.33%) answered with a focus on residents' quality of life. The remaining thirteen participants (86.67%) responded with mechanical answers, considering skills rather than quality of life. For example, one participant commented, "I felt so bad, they couldn't really physically tell me what they wanted, so I'd always start with a drink first and then give some food to them, and sometimes they would close their mouth and turn their heads away, but then if they don't eat anything… It was really hard to tell what they wanted." On the other hand, another participant explained, "That thickening stuff, most of the time I only see that happen with the non-dementia patients," due to the communication barrier between staff and dementia residents, who are less able to express their difficulties verbally and rely on the aides to pick up on non-verbal cues. Of concern, a participant recalled a close call with a resident who was not assigned a modified diet, but likely needed one. She said,

> "Well, one of them choked and almost died on me… Yeah one time, freak story, this dude choked on a piece of meat, and he wasn't [one of] our feeder patients so, like, the guy in the kitchen was like 'Hey, [name], this guy isn't okay' and I'm like 'Oh he's fine, he always sleeps during supper. He's like 'no, like he's blue' and I'm like 'Oh!' So I turn around and he's like [laying back] in his chair, so I Heimliched him and then he was fine. It was terrifying."

While most respondents noted their experiences mechanically in terms of skills rather than quality of life, they show the need for more attention to dysphagia care.

Question 5: How prepared did you feel upon beginning your job to feed dysphagia patients in a safe and dignified manner? Now?

Upon beginning their first job as a CNA or medication aide, only four (26.67%) participants felt prepared and confident to feed dysphagia residents. Eleven (73.33%) recalled feeling unprepared to feed dysphagia residents. One participant expressed her apprehension by saying, “I was very nervous, I was super nervous. I was scared they were gonna aspirate.” Another said, “Honestly at first, [I was] kind of terrified because I feel like you don’t get a lot of training about it, like it’s kind of glossed over in CNA class and then in my four days of training at [place] I don’t feel like it was really talked about at all…”

When asked how they felt to feed dysphagia residents now, or at the end of their experience as a CNA or medication aide, thirteen (86.67%) noted they felt prepared at that point, while two (13.33%) said they were unprepared still, explaining they felt apprehensive or still had questions. Prepared or not, all 15 (100%) participants expressed they gained confidence in providing dysphagia care as they gained hands-on clinical experience.

Question 6: Tell me about the training you received to feed/care for dysphagia patients? Was it sufficient? If it is not sufficient, why not?

The results for question six were separated into two categories, CNA class training for dysphagia care and employer-based dysphagia training. Employer-based training includes new hire training and on the floor orientation. The categories for the response are insufficient or

sufficient. Insufficient class training groups three subcategories, including brief dysphagia training that was insufficient, general feeding training nonspecific to dysphagia, or no training at all. Four of fifteen (26.6%) noted they only received training in regard to feeding, but not specific to dysphagia care. Six of fifteen (40%) reported receiving no dysphagia feeding training at all. One participant (6.67%) recalled brief, but insufficient dysphagia training. In regard to CNA class training, eleven (73.33%) participants categorized their training as insufficient, and four (26.67%) categorized their training as sufficient. A participant responded, "Class training was completely insufficient because there was none." In contrast, another participant was satisfied with the level of training received in class, which she expressed "I feel like it was sufficient. When I got my training, they brought out the thickened liquids and made us try it to show us what it's like for them. It was part of the empathy factor." In regard to employer-based dysphagia training, eleven (73.33%) categorized their training as insufficient, and four (26.67%) categorized their training as sufficient. Seven (46.67%) participants categorized both their CNA class training and employer-based training insufficient, meaning that the entirety of their dysphagia training was self-taught. As one participant expressed, "I don't think we got any of that in CNA class. As far as my on the job training, same, I mean the CNA who trained me like barely trained me." Eight (53.33%) participants categorized at least one of their training sessions, either CNA class or employer-based, as sufficient.

Question 7: What is your biggest barrier for being able to provide the best care to patients with swallowing difficulties?

The results for question seven are categorized into four different groups. The categories include 1. staffing 2. education, 3. dietary, and 4. communication. Dietary barriers include lack

of adaptive utensils, the residents understanding the necessity for their modified diet, the residents enjoying their modified diet, and inaccurate assessment for the need of a modified diet, such as a resident needing a dysphagia diet but not being assigned one. Four (26.67%) participants reported staffing as their number one barrier, four (26.67%) reported needing more education about dysphagia care, and four (26.67%) reported dietary problems. Three (20%) participants reported communication with resident as their top barrier to provide the best care to dysphagia residents. A participant noted communication as her biggest barrier,

> It's really hard to get them to slow down...you also have to do like very minute directions because they have to have time to process it ...so you have to break up the directions, but then they also have to remember it. So that would be beneficial to me if somebody could teach me how to do that more efficiently.

Another participant reported lack of dysphagia education as her barrier, noting "Besides lack of information, like I'm not even sure how to do it. That is an essential thing." A different participant struggles mostly with staffing, reporting "I work on a smaller floor so I'm the only CNA there, so if I have two dysphagia patients I'm screwed and there goes my whole day." Additionally, a participant expressed her concerns with the appearance of the food,

> A lot of the time [the biggest barrier] is decent food. That is really hard for them. Like if it doesn't taste good, they don't want it. Or the texture, the appearance of the food. With dysphagia [level] one, you always have the appearance, it doesn't look good, or I guess that could be another one - the patients wanting to follow that diet.

Question 8: How do your regular tasks impact the care dysphagia patients receive?

The responses for this question were separated into two categories. The first category shows the participant believed their regular tasks, i.e. workload, does **not** impact the quality of care dysphagia residents receive. The other category shows the participant believed their regular tasks **decreased** the quality of care they were able to give their dysphagia residents. Of the fifteen participants, four (26.67%) recalled their regular tasks did not impact the quality of dysphagia care. Eleven (73.33%) participants recalled their regular tasks, i.e. workload, decreased the quality of dysphagia care they were able to give their patients. A participant noted that all the dysphagia residents have to sit at the same table, "We would always feed everyone else first and then the people we did have to feed, we all sat them at one table and fed them together so it did take more time." Someone else stated,

> CNAs are expected to do a lot for the patients, and I think teamwork within nursing and med aides would be a lot more beneficial and everything would run a lot more smoothly...There's people I work with where I know 'I'm gonna get a lot of help today' and then there's also people I work with and I'm like, 'Yeah, I'm all on my own today.' It needs to be more of a team effort, but that's also just like every job, but healthcare is where it needs to be more effective because you have to have those people who genuinely enjoy helping people. Some people are there for the paycheck and some people are there to help.

Question 9: How can the barriers you described earlier be lessened or reduced?

Of the fifteen responses, seven participants (46.67%) reported increasing staff to resident ratios would be the most beneficial solution to increase the quality of care residents with dysphagia receive. One participant said, “I think the easiest way is to hire more aides and have a higher aide to patient ratio. We never had enough aides to feed.” The next most commonly reported answer was reported by five participants (33.33%), who said more education about dysphagia care would lessen their barriers and allow them to provide better care. A participant explained,

> I think it would be really beneficial to just actually talk about how to care for dysphagia patients in CNA training and also to kind of-- I think by doing that it would reduce the being scared about it because it does seem really scary to have a patient with swallowing difficulties, and you’re like “Oh, what if I do something wrong and they choke and die?” but if you actually know what you’re doing you realize it’s really not that scary, you just need to alter a few things. It’s really really intimidating at first.

Three participants (20%) noted dietary modifications including adjusting meal times, serving more appetizing food, and having dietary needs clearly listed for staff would be most helpful in reducing their barriers to high quality dysphagia care. A suggestion made by a participant was, “Come up with a different way of preparing dysphagia food. I know they have molds you can put them in and we use that, and it does help but maybe find different ways or flavors or different foods too because it seems to be the same foods over and over. More variety for patients.” Another said,

> I think a way to counteract that would be to do early trays, late trays for patients who take longer and have special needs… just have the whole team come together, 'Okay, we need to go feed these six patients a half hour early' so we can get that done so they can take their time and still enjoy their meal, and not be rushed… Most people eat in their rooms, as long as they're not cognitively impaired or something like that."

Question 10: In what ways do you learn best?

This question had a majority response of mixed methods with eight (53.33%) participants noting more than one type of learning style. These styles included hands-on (6), demonstration (4), constructive criticism (2), listening (2), practice (1), reading (1), powerpoint (1), and videos (1). Of those who answered with just one method of learning, five participants (33.33%) reported hands-on, one (6.67%) reported videos, and one (6.67%) reported pictures were most helpful.

Question 11: What sort of training/education would be of help to you in providing dysphagia care? For example, online courses, reading, video tutorials, role playing.

In specific regard to dysphagia care training, four participants (26.67%) reported mixed methods, including videos (4), hands-on (3), online (1), and role playing (1). Of those who listed one method as their preference, five (33.33%) favorited hands-on, two (13.33%) reported online, two (13.33%) reported videos, one (6.67%) said role playing, and one (6.67%) said pictures. Hands-on and mixed methods are the leading learning techniques among the participants.

Question 12: What differences would you like to see in regard to how patients with swallowing difficulties are cared for?

Of the fifteen participants, seven (46.67%) responded to this question emotionally, concerning the patients' dignity and quality of life, while eight (53.33%) gave education-based responses concerning training, skills, and staffing. One participant shared,

> I feel like we need to definitely level up the priority a bit because all their day is centered around meal time. They get up, breakfast, chill until lunch, chill even longer until dinner. Like it's really centered around food and being able to eat. It's one of their favorite pastimes I'm sure, so being able to make that a more desirable and enjoyable time for them... [Room Number] was on hospice, and she was for a long time. She was degrading so much, and she didn't eat most of the time. Her mouth and lips were so dry and I'm sure she had just like no saliva to move stuff around and I felt like we did nothing for it. She didn't even have that thickening stuff, she didn't eat or drink anything for months. I feel [Director of Nursing] absolutely knew what was going on and she chose not to do anything about it.

This being said, another participant emphasized the need for compassionate care for dysphagia patient by saying,

> Not rush them so much. It's really easy to do, we're all guilty of it when we're super short-staffed, we try to feed them. Something I always try to do is feed them until they're ready to not eat anymore because it's really easy just to stop feeding because it's taking

> too long or it's like 'oh, they ate half their meal…' but I like to eat my full meal so they probably do too. I feel like that leads to all sorts of issues. If you're not feeding them everyday then they're not getting proper nutrition.

It was interesting to find the trend among emotional reactions for this question heavily pointing toward the way dysphagia residents are overlooked and only helped when there is time for the staff to do so. Based on this limited sample, it would appear dysphagia residents seem to often be the lowest priority in resident care.

The other main trend in the results had to do with the need for skills training and enhanced quality of care. One participant noted,

> They need more time and effort...I mean, they need their own person sometimes it feels like. You need to plan more time for them which is hard to do, especially in a long term care facility when there isn't a lot of help.

Another added,

> I would add more training to the actual nurse aide training. I mean it's not like that's a skill you have to check off on, at least in the Nebraska training, so I think that would be important, especially with a lot of nurse aides going to work in nursing homes, that's a big issue there, and you're not accurately trained [in aide training class] and then you're not accurately trained there either, then that's a big problem.

Discussion

In ten years, for the first time in the history of the United States, adults aged 65 and older will outnumber children (Gibson, 2018). There is currently an estimated 52,423,114 people 65 and older in the U.S. out of the total population of 327,167,439 (United States Census Bureau, 2018). From now to 2030, the percent of the population age 65 and over is projected to increase from 16% to 20% (United States Census Bureau, 2018). With an ever-increasing number of senior citizens in our country, it is urgent that they are receiving the highest quality care possible. Soon, one-fifth of the U.S. population will be at least 65 years old and they cannot be looked over any longer (United States Census Bureau, 2018).

This study investigated common barriers and potential solutions for frontline workers providing care to dysphagia residents. If the barriers and solutions are identified, nursing facilities can make headway toward positive changes in maintaining residents' dignity and quality of care. A limited sample of CNAs and MAs from across the continuum of care reported answers for twelve interview questions.

The common interview responses indicated a perceived lack of proper education about dysphagia and how to provide dysphagia care from both their formal CNA class and employer training. Their lack of training resulted in feelings of guilt and uncertainty. When someone goes to the dentist, mechanic, hair stylist, and so on, they expect the service they are paying for will be provided by someone with thorough training and high competence in skills. Despite older adults' right to quality care regardless of conditions, age, or skills, they also pay thousands of dollars for nursing care. A person would not want to get a cavity filled by someone whose dental school skipped over that topic. Furthermore, these examples are not a matter of life or death, while dysphagia care impacts residents with dysphagia's entire day, every meal, and can be fatal,

whether by slow malnutrition or quick aspiration. Most participants felt unprepared to feed dysphagia residents when they started their job, showing the continued need for proper training from CNA and MA classes as well as on-the-job training. As with most jobs, there are usually some aspects new employees are nervous about and have to adjust to or self-teach. However, feeding human beings who depend on aid from others, who are likely already dealing with feelings of shame and low self esteem, is not a skill that should be up to the aide to learn as they go. Sending an uneducated aide onto the floor to feed a resident with dysphagia can result in undernutrition, dehydration, aspiration pneumonia, and even death. We must demand better for our seniors.

Next, common interview answers indicated participants' felt their workload decreased the quality of care their residents received. The pressure and necessity to accomplish a certain set of regular tasks each shift removes essential time aides need in order to feed residents with dysphagia carefully, safely, and until the resident reaches a sufficient satiety. Disregarding the needs of older adults with dysphagia in order to accomplish other tasks deemed more important, such as baths, toileting, getting residents to bed, is unsafe and should not be accepted as quality care.

The most commonly reported largest barriers for providing high quality care to residents were understaffing, lack of proper education, and dietary-related problems, such as lack of assistive devices or attractiveness of food served, and communication. By adding thorough dysphagia education and care training for frontline employees, two of the four largest barriers can be reduced. Dysphagia training should include communication techniques as well as feeding and swallowing methods. Training should expand further than basic mechanical skills on how to feed dysphagia residents and what skills to teach the resident to enable them to swallow more

easily, but also incorporate communication and feeding styles that empower the resident and enhance their sense of self worth and self-esteem. With open communication with dietary staff, obtaining the needed assistive devices and broadening options for modified diets, the dietary barrier could also be lessened. In a more perfect world, staffing issues could be addressed head on by adding aides to each shift, but budgets are often too tight for this addition. An option to be considered is adding an aide only for the meal times. This way, there is an extra person to oversee the dining area and assist with residents with dysphagia who need more help at this time, without having to pay for an entire added shift.

Changes should be made to assist CNAs and MAs in supporting nursing facility residents with the highest quality of care possible. Participants suggested increasing staffing, increasing the amount and quality of education, and accommodating dietary needs as ways to lessen the barriers they face. While increasing staffing can be difficult due to budget restraints, a more feasible solution seems to be increasing dysphagia education provided to these frontline workers. Participants reported preference toward a mixed methods style of learning, including mainly hands-on experience, but also demonstrations, constructive criticism, listening, practice, reading, powerpoints, and videos. Specifically related to dysphagia, participants suggested mixed methods including hands-on, videos, online, and role playing. Others suggested solely hands-on, online, role playing, videos, and pictures, with the majority preferring hands-on.

Participants reported wanting to see changes in the way residents' quality of life is valued as well as the amount of education received, so dysphagia training should prioritize empathy and importance of older adults' dignity, life satisfaction, and happiness in addition to mechanical skills to ease swallowing difficulties and manage dysphagia. Adding in refresher modules about dysphagia care, communication, and valuing resident dignity could help boost continuously

high-quality care given by confident, competent aides. Many facilities already have ongoing training modules, often online, that employees must complete before a certain deadline.

Multiple participants noted all dysphagia residents sit near each other in order to make the CNA and MAs jobs easier, which could inadvertently ostracize residents. In a study conducted with 395 nursing home residents, the "number of dining companions was positively associated with quality of life in both cognitively impaired and cognitively intact residents. This association may reflect the fact that dining with others increases social interaction, which has been found to be a key component of quality of life" (Carrier, West, & Oulle, 2009). The residents in the study reported choice of dining companions and meal location as their top priorities in aspects that impact their qualities of life (Carrier et al., 2009). Sitting dysphagia residents with non-dysphagia residents could help them feel included and build relationships with fellow residents. Forcing residents to sit in certain spots every day dismisses the residents' preferences and autonomy.

Since communication was another common barrier reported in the study, dysphagia training should include communication techniques for engaging with dysphagia residents, who can be non-verbal or have difficulty speaking verbally. If a dysphagia resident cannot express their needs and preferences to those taking care of them, they are likely to feel discouraged and misunderstood. If frontline workers have knowledge of communication techniques, their residents can receive more individualized care to meet their needs and have real conversations with staff.

In a study conducted with speech pathology students, one group received training on communication strategies for those with speaking difficulties, called aphasia, that commonly accompanies dysphagia, and one group received no training (Finch et al., 2017). Then, both

groups had conversations with people with aphasia, and their skills were calculated using the Measure of skill in Supported Conversation (MSC) scale (Finch et al., 2017). MSC scores are based on areas including ensuring the person with aphasia understands the conversation, verifying what the aphasia resident had communicated, and ensuring the person was actively involved in conversation. The group who received communication training had higher MSC scores, used more props, writing, and gestures, and introduced more topics into the conversation (Finch et al., 2017). Advancing aides' skill set and confidence to engage with those who have speaking difficulties helps the resident feel included, valued, and allows them the human contact they deserve (Finch et al., 2017). Dysphagia residents deserve to have a good life experience regardless of their impairments, and CNAs and MAs need to be trained in order to provide high quality, individualized care.

According to Peladic et al., (2019) dysphagia residents have a 37% higher mortality rate than non-dysphagia residents. This is likely due to complications including nutritional deficits and aspiration pneumonia (Peladic et al., 2019). Those with feeding tubes live, on average, one year longer than those who rely on assistance from staff (Peladic et al., 2019). When frontline staff does not have sufficient staffing nor skills to sufficiently feed dysphagia residents, they likely lack key nutrients and caloric intake. Undernutrition can deteriorate cognitive ability and the immune system and lead to weight loss and poorly healing pressure ulcers (Peladic et al., 2019). Since low quality dysphagia care decreases quality and length of life, it is imperative that frontline workers are receiving proper, detailed, continuous training to provide dignified, thorough dysphagia care to this underserved population.

Some of the aides interviewed alluded to feelings that their workload demands fast paced work that can lead to marginalized dysphagia care. Dysphagia is generally correlated with

malnutrition (Namasivayam-MacDonald, 2017). Within nursing homes, malnutrition is a continuous health problem for residents, as a result of several potential factors including understaffing (Blumberg et al., 2018). Dysphagia and malnutrition are associated with hindered recovery from illness and injury, increased need for long-term care assistance, longer hospital stays, and aspiration pneumonia, consequentially associated with increased morbidity and mortality (Namasivayam-MacDonald, 2017). A study by Bell et al. states malnutrition is associated with cognitive and functional impairment, as well as depression and dysphagia (2015). Therefore, if dysphagia residents are receiving sufficient meal time assistance, and their nutrition is properly maintained, their functional ability will be maintained and they may live healthier, stronger lives.

This study has several limitations. The small sample size of only fifteen participants limits results. The limited sample size means results cannot be generalized to a larger population. Because it was a qualitative study, a snowball sampling technique was used to identify participants. This led to multiple participants from the same workplace, which then led to similar experiences. There is a need for further research to better understand the challenges faced by CNAs and MAs. Further research can help us identify the gaps in care and how these gaps can be filled.

The qualitative study was performed in order to determine the most prevalent barriers for frontline workers in providing high quality, dignified care to dysphagia residents. Based on the results of this study, there is an opportunity to enhance the quality of care of older adults with dysphagia by offering additional aides and workplace training to ensure elders are not harmed because of a lack of knowledge/education on proper feeding techniques. The results from the limited participants of this study showed a majority desired extra staffing during mealtimes. If

this is absolutely not possible for a facility, perhaps a volunteer program could be set up. The certified volunteer could either deliver plates to non-dysphagia residents if there is a liability issue, or help feed dysphagia residents one-on-one to lend a hand to those working. One study done in Sydney, Australia by Huang et al., demonstrated that "Trained volunteers that assist 'at risk' and malnourished residents at lunch meals have been shown to effectively increase nutritional intake in a suburban hospital in Sydney, [Australia]" (2015). Five of the volunteers from this study completed a follow up questionnaire in which all five agreed there was a need for the program and felt it was beneficial (Huang, 2015). Eight nurses completed the survey, seven reporting the volunteer program as "very helpful" with the last nurse ranking it as "moderately helpful" (Huang et al., 2015). The general consensus among nurses at the facility was that the Sydney hospital volunteer program gave them extra time to complete their tasks, one of the major issues found in this research study (Huang et al., 2015).

The findings indicated a need to add or enhance dysphagia education and dysphagia-specific training for CNAs and MAs in the classes required for certification and on-the-job for this group of respondents. Adding a unit about the signs, risks, effects, and proper care for dysphagia in CNA and MA certification classes would initiate some dysphagia education. Further, hire-on training at workplaces and on-the-job training during orientation could solidify previous knowledge and build skills. One participant recalled hire-on dysphagia training from a speech pathologist as very beneficial. Including dysphagia training in class and in the workplace would help aides feel confident and perform competently. Having well trained staff or volunteers help feed dysphagia residents could enhance the residents' nutritional status and quality and longevity of life. By making the needed adjustments to reduce these barriers CNAs and MAs face, dysphagia residents can be served in a higher quality of dignified care.

Reflection

Through interviewing certified nursing assistants and medication aides, I could identify shared barriers faced in providing dysphagia care and make possible suggestions for what changes can be made to provide higher quality, personalized care instead of medicalized care to older adults with dysphagia. There was a clear lack of education about dysphagia and training on dysphagia management for the frontline workers who assist with activities of daily living such as eating. Aides were terrified and unprepared to feed dysphagia residents, having minimal or no training on this skill that could be a life or death matter. I was also able to learn how important meal times are for nursing facility residents, and the social and emotional implications faced by those with dysphagia. I was able to identify possible solutions to fill the cracks in senior care facilities to give dysphagia residents more meaningful, fulfilling meal times and lives in facilities.

In all, I was able to give a voice for residents with dysphagia who may otherwise be overlooked. In the future, I hope to work in health care and provide for each unique patient in ways that best meet their individual needs, rather than doing what is most convenient for me. I will continue to advocate for our older adults and empower positive changes in the way patients and residents are cared for.

A Qualitative Analysis of the Barriers Faced by Nursing Assistants and Medication Aides in the Care of Dysphagia Patients

Lauren Kreuzberg

Pursuing Bachelor of Science in Nutrition Science (UNL)
& Bachelor of Science in Gerontology (UNO)

University of Nebraska-Lincoln Honors Program

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UNIVERSITY OF NEBRASKA AT OMAHA
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Abstract

Dysphagia refers to the symptom of difficulty swallowing that accompanies several prevalent conditions in the older adult population, including amyotrophic lateral sclerosis (ALS, Lou Gehrig's Disease), stroke, Parkinson's Disease, Multiple Sclerosis, dementia, various cancers, and brain tumors (Allari, 2014). Many older adults who suffer from these conditions reside in nursing facilities, where most of their care is provided by certified nursing assistants (CNAs) and medication aides (MAs). However, the extent of these workers' knowledge and competence in providing care to nursing home residents with dysphagia is vastly unresearched. The qualitative analysis investigates themes among interviews with fifteen CNAs and MAs regarding their experiences and perceived barriers caring for residents with dysphagia. The participants identified barriers to providing excellent dysphagia care including low staff to resident ratio, lack of proper education, and dietary issues. The responses show the need for dysphagia care education in the formal CNA and MA training and during on-the-job training. Though additional research is needed, there seems to be an immediate need for intervention in educating frontline workers about how to care for residents with dysphagia in a safe, dignified manner.

Key words: Dysphagia, CNA training, medication aide, certified nursing assistant, CNA, swallowing difficulty

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Objectives

1. Identify barriers nursing aides and medication aides face in giving high quality dysphagia care to seniors
2. Explain frontline workers' experiences and perceptions of how dysphagia patients are treated
3. Discuss how to enhance the quality of care dysphagia patients are receiving from nursing aides and medication aides

Literature Review

- Dysphagia: difficulty swallowing
  - Failure of sensory or motor mechanisms that transport bolus through mouth, pharynx, esophagus
  - Signs: pocketing food, drooling, coughing

- People with dysphagia may have no signs, feel their life is less enjoyable, suffer from panic attacks and anxiety, avoid eating in front of others, eat less, and stop eating when they are still hungry

Garcia, J. M., & Chambers IV, E. (2010). Managing dysphagia through diet modifications. *AJN The American Journal of Nursing 110*(11), 26-33.

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Literature Review

Dysphagia Management

- Dietary modifications include change of texture and consistency
- Nectar-like (1), honey-like (2), spoon-thick (3)

Level of Dysphagia Diet	Food consistency
Level 1	Pureed
Level 2	Soft foods, i.e. pancakes, custard
Level 3	Solid foods, i.e. cereal, eggs, meat
Level 4	Regular diet

Garcia, J. M., & Chambers IV, E. (2010). Managing dysphagia through diet modifications. *AJN The American Journal of Nursing 110*(11), 26-33.

Literature Review

Artificial Nutrition and Hydration

- Becomes necessary when dysphagia advances and swallowing is impossible
- Dysphagia is often unrecognized
- Common contributors: Dementia, cancer, ALS, stroke, Parkinson's Disease, Multiple Sclerosis

ANH Options

- Enteral: Feeding into GI tract, less than six weeks
- Parenteral: Long term placement of feeding device into large vein for direct entry to bloodstream

Acreman, S. (2013). Nutrition in palliative care. *British Journal of Community Nursing,14*(10),
Allari, B. H. (2014). When the Ordinary Becomes Extraordinary: Food and Fluids at the End of Life. *Generations,*86-91. Retrieved November 26, 2018.
Brady, G. C., Roe, J. W., Brien, M. O., Boaz, A., & Shaw, C. (2017). An investigation of the prevalence of swallowing difficulties and impact on quality of life in patients with advanced lung cancer. Supportive Care in Cancer,26(2), 515-519. doi:10.1007/s00520-017-3858-6
Payne, M., & Morley, J. E. (2018). Dysphagia, dementia and frailty.

Literature Review

Respecting Patient Choice

- Differences in culture, values, comfort, religion
- Keep patient informed and respect unique experiences and choices
- Inform family of importance of respecting inability to eat and associated choices

Person-Directed Care

- Individualize instead of medicalize care
- Give each resident a special experience that caters to their preferences, needs, and personalities

Acreman, S. (2013). Nutrition in palliative care. *British Journal of Community Nursing,14*(10),
Gillespie, L., & Raftery, A. (2014). Nutrition in palliative and end-of-life care. Nutrition and Palliative Care, S15-S20. Retrieved November 26, 2018.
Shune, S. E., & Linville, D. (2019). Understanding the dining experience of individuals with dysphagia living in care facilities: A grounded theory analysis. International journal of nursing studies, 92, 144-153.

Literature Review

Role of Certified Nursing Assistants and Medication Aides

- Skilled communication among team vastly enhances resident experience
- Residents can tell which aides having more caring intentions
- Staff should allow residents to choose their seats rather than grouping residents by diagnosis or level of need
- Aides are generally apprehensive and may have received no formal training concerning dysphagia management upon entering the role
- Staff commonly has desire to help more than the level allowed by staffing ratios
- CNAs provide 80% of care

Chiang, C. K., & Hwu, Y. J. (2018). Feeding experiences of nursing aides for residents with dysphagia. Geriatric Nursing, 39(4), 436-442.
Shune, S. E., & Linville, D. (2019). Understanding the dining experience of individuals with dysphagia living in care facilities: A grounded theory analysis. International journal of nursing studies, 92, 144-153.

Methodology

- Qualitative research
  - Details, firsthand experiences
  - Allow participants freedom to share
- 12 questions
- Recruitment
  - Snowball sampling
- Interview
- Data Analysis
  - Thematic analysis
  - Organized by question
  - Similar experiences grouped
- Ethical Standards
  - Approved by University of Nebraska-Lincoln Institutional Review Board

Participants

Certification Date	# Participants per Year
2014	1
2015	5
2016	2
2017	3
2018	4

	Years of Experience
Mean	2.52
Range	6 months to 6 years

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Participants

Setting	# Participants per Setting
Long-Term Care	7
Rehabilitation	3
Hospital	2
Memory Care	2
Home Health	1
Total Participants	15

Interview Questions

1. How many years have you worked as a CNA/Medication Aide?
2. In what settings have you worked as a CNA/Medication Aide? I.e. hospital (wing?), skilled nursing, rehabilitation, assisted living, memory care, hospice.
3. Approximately what year did you receive your aide training?
4. Tell me about your experiences providing care to dysphagia patients.
5. How prepared did you feel upon beginning your job to feed dysphagia patients in a safe and dignified manner? Now?
6. Tell me about the training you received to feed/ care for dysphagia patients? Was it sufficient? If it is not sufficient, why not?

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Interview Questions

7. What is your biggest barrier for being able to provide the best care to patients with swallowing difficulties?

8. How do your regular tasks impact the care dysphagia patients receive? I.e. workload

Future Training

9. How can the barriers you described earlier be lessened or reduced?

10. In what ways do you learn best?

11. What sort of training/education would be of help to you in providing dysphagia care? For example, online courses, reading, video tutorials, role playing.

12. What differences would you like to see in regard to how patients with swallowing difficulties are cared for?

Results

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Tell me about your experiences providing care to dysphagia patients.

Theme	Quality of Life	Mechanical Skills
Percent of Respondents	13.33%	86.67%
	"Well, one of them choked and almost died on me… Yeah one time, freak story, this dude choked on a piece of meat, and he wasn't [one of] our feeder patients so, like, the guy in the kitchen was like 'Hey, [name], this guy isn't okay' and I'm like 'Oh he's fine, he always sleeps during supper. He's like 'no, like he's blue' and I'm like 'Oh!' So I turn around and he's like [laying back] in his chair, so I Heimliched him and then he was fine. It was terrifying."	"That thickening stuff, most of the time I only see that happen with the non-dementia patients because like we figured out they need that and it's a lot harder to figure out with dementia"
	"I felt so bad, They couldn't really physically tell me what they wanted, so I'd always start with a drink first and then give some food to them, and sometimes they would close their mouth and turn their heads away, but then if they don't eat anything…"	"We just kind of double check and make sure they have the right type of food. We have a lot of people on thickened liquids too, so just making sure they have the right liquid."

How prepared did you feel upon beginning your job to feed dysphagia patients in a safe and dignified manner? Now?

Theme	Unprepared (Beginning)	Prepared (Beginning)
Percent of Respondents	**73.33%**	**26.67%**
	"I was very nervous, I was super nervous. I was scared they were gonna aspirate."	"I felt very prepared from CNA class and then again through the training at the facility I work at."
	"Honestly at first, [I was] kind of terrified because I feel like you don't get a lot of training about it, like it's kind of glossed over in CNA class and then in my four days of training at [place] I don't feel like it was really talked about at all…"	I feel like I felt prepared, like I knew what it was. But as a CNA, I didn't know much beyond what I needed to know. I knew enough. Then I feel like it was just a matter of getting comfortable with people who had it."

How prepared did you feel upon beginning your job to feed dysphagia patients in a safe and dignified manner? Now?

Theme	Unprepared (Now)	Prepared (Now)
Percent of Respondents	**13.33%**	**86.67%**
	I would still say I'm a little apprehensive, not as much as when I started but still like 'eh.' I would sit there, and sometimes they would get mad...and point to it… or I go too fast and they pull away and I'm scared they're gonna pull away"	"I feel a lot more better but I've also been in the field for 4 years, so I kind of learned more by experience than teaching… I learned it from experience and being able to help my patients when I'm with them."

Tell me about the training you received to feed/ care for dysphagia patients? Was it sufficient? If it is not sufficient, why not?

CNA/MA Formal Class Training		
Theme	Insufficient	Sufficient
Percent of Respondents	73.33%	26.67%
	"Class training was completely insufficient because there was none.	"It was, yeah, definitely. So in my CNA class, you had to do like do a skill of feeding a patient and then there was another one of feeding ones with dysphagia. Just making sure you know they're upright in bed, small bites with water, you know. So I felt prepared."
	"Not sufficient. They don't really focus on it at all. It's just kind of like an acquired education…"	"I feel like it was sufficient. When I got my training, they brought out the thickened liquids and made us try it so show us what it's like for them. It was part of the empathy factor"

Tell me about the training you received to feed/ care for dysphagia patients? Was it sufficient? If it is not sufficient, why not?

Employer-Based Training		
Theme	Insufficient	Sufficient
Percent of Respondents	73.33%	26.67%
	They just kind of tell you how to feed a patient and it's more so just 'here, feed them, slow, make sure their food's not too hot.' It's never like specifically with a dysphagia patient."	"I was super blessed to have the woman training me when I started as a CNA. She was a CNA at that hospital for 26 years, so she knew all the ins and outs and I feel like she gave me great training on how to safely handle dysphagia."

What is your biggest barrier for being able to provide the best care to patients with swallowing difficulties?

Theme	**Understaffing**	**Lack of Education**	**Dietary Issues**	**Patient Communication**
Percent of Respondents	26.67%	26.67%	26.67%	20%
	"I would say time is a big one just because you do have to take a lot more time with dysphagia patients and you know it requires a lot of patience and encouragement and sometimes on a crazy shift you don't have enough time for that"	"Honestly, just education. In training, when I started my new job, they give you a few days of training, and they go over feeding and basic reminders, but they don't go into depth about dysphagia patients or even just on the floor you kind of just assume who has dysphagia because of their diet but it's never really said straightforward like 'this person, feed them slowly or do this or take small bites like stuff like that."	A lot of the time [the biggest barrier] is decent food. That is really hard for them. Like if it doesn't taste good, they don't want it. Or the texture, the appearance of the food. With dysphagia [level] one, you always have the appearance, it doesn't look good, or I guess that could be another one - the patients wanting to follow that diet."	"I'd say if they can't speak, that's the biggest. If they're able to talk and be like 'oh can I have that bite next, or I'm ready' that's so much easier than having to assume and look into their mouth"

Theme	Understaffing	Lack of Education	Dietary Issues	Patient Communication
Percent of Respondents	26.67%	26.67%	26.67%	20%
	"Now I feel like my biggest barrier is just finding time. I work on a smaller floor so I'm the only CNA there, so if I have two dysphagia patients, I'm like screwed and there goes my whole day."	"Besides lack of information, like I'm not even sure how to do it. That is an essential thing."	"The lack of tools. A lot of dysphagia patients do better with the cups they can hold themselves with a lid and the special forks. A lot of facilities, like you have to request it to get those at the facility and a lot of the time therapy just doesn't request it and it's just annoying…then I had to feed them when they potentially could have been taking care of themselves, especially in the rehab setting where they're supposed to be becoming more independent."	"I feel like it was hard, judging like what - when you're feeding someone - like what they want next, like you just kind of have to guess, but you also **don't want to take away that autonomy from them**, so I think like that part of it was kind of just hard because you don't want to force them…"

How do your regular tasks impact the care dysphagia patients receive? I.e. workload

Theme	Does Not Impact Care	Decreases Quality of Care
	26.67%	73.33%
	"I feel like it's a lot to do but the nurses on my floor are very helpful and understanding because patients have to eat and drink so they understand if I'm spending time in that room."	"You can't really be in the dining room sometimes with your dysphagia patients because you have other things you have to finish before, so they have an increased risk of choking and no one noticing because you're not in the dining room all the time. Especially like taking people back to their rooms."
	"It wasn't bad at all, most the times I worked nights… I would just make him dinner and then feed him dinner, so most the time it didn't really impact it too much. There wasn't a lot I had to do."	"At [workplace], we would always feed everyone else first and then the people we did have to feed, **we all sat them at one table** and fed them together so it did take more time. You just kind of had to plan for it. You'd get someone out there early and then sit out there more and more...We were always running around"

How can the barriers you described earlier be lessened or reduced?

Theme	Increase Staffing	Increase Dysphagia Education	Dietary Modifications
	46.67%	33.33%	20%
	"I think the easiest way is to hire more aides and have a higher aide to patient ratio. **We never had enough aides to feed.**"	Just continuous educational training. Like I said I learned everything mostly on my own and I just don't think that's beneficial and some people still don't pick up on those cues even after being a CNA for so long. You kinda have to trial and error with people, as bad as that sounds because you're handling people's lives but that's what you have to do, and I'm still learning.	I think a way to counteract that would be do early trays, late trays for patients who take longer and have special needs…just have the whole team come together and like 'OK we need to go feed these six patients a half hour early' so we can get that done so they can take their time and still enjoy their meal and not be rushed…Most people eat in their rooms, as long as they're not cognitively impaired or something like that."

How can the barriers you described earlier be lessened or reduced?

Theme	Increase Staffing	Increase Dysphagia Education	Dietary Modifications
	46.67%	33.33%	20%
	I always think they should have one extra aide that just helps during mealtimes and strictly just feeds people because when we're just running all over the place we don't have time to sit down for like a half hour to feed.	"I think it would be really beneficial to just actually talk about how to care for dysphagia patients in CNA training and also to kind of- I think by doing that it would reduce the being scared about it…"	"I don't know, come up with a different way of preparing dysphagia food. I know they have molds you can put them in and we use that, and it does help but maybe find different ways or flavors or different foods too because it seems to be the same foods over and over. More variety for patients."

In what ways do you learn best?

Themes	Mixed Methods	Hands-on	Pictures	Video
	53.33%	33.33%	6.67%	6.67%
	"Listening to instructions and then doing, practicing"	"I would say hands on is probably the best, and then doing it. Practicing it"	"I mentioned earlier but I really do like the pictures"	"Videos, examples"

What sort of training/education would be of help to you in providing dysphagia care? For example, online courses, reading, video tutorials, role playing.

Themes	Mixed Methods	Hands-On	Online	Videos	Role Playing	Pictures
	26.67%	33.33%	13.33%	13.33%	6.67%	6.67%
	"At [workplace], what helped me personally was an online course and video tutorial they made you watch. And then also doing the role play where we had to pretend to be dysphagia patients really helped a lot too."	"I think just, like at orientation time, just the hands on training provided by nurses. I think what would be really useful to see, to practice on yourself what the swallowing strategies do, so like, practice swallowing with a chin tuck, you know what I mean? Try the strategies out so they're really engrained in your head so you know how they help and when you see someone have a difficulty you kind of make that connection for them. I think that would be really helpful.	I think having some sort of online module would be more helpful than just having a list of things to read because it's telling you what to do and you're seeing it at the same time."	I would say videos, I think that's the best way to show how slow you wanna feed them or how small to make the bites."	"Role playing I guess so you just have it front of you and see exactly what you're supposed to be doing."	"I would say pictures still."

What differences would you like to see in regard to how patients with swallowing difficulties are cared for?

Themes	Quality of Life-Based	Education-Based
	46.67%	53.33%
	Not rush them so much. It's really easy to do, we're all guilty of it when we're super short-staffed, we try to feed them. Something I always try to do is feed them until they're ready to not eat anymore because it's really easy just to stop feeding because it's taking too long or it's like 'oh, they ate half their meal…' but I like to eat my full meal so they probably do too. I feel like that leads to all sorts of issues. If you're not feeding them everyday then they're not getting proper nutrition.	They need more time and effort...I mean, they need their own person sometimes it feels like. You need to plan more time for them which is hard to do, especially in a long-term care facility when there isn't a lot of help.

Themes	Quality of Life-Based	Education-Based
	46.67%	53.33%
	"I feel like we need to definitely level up the priority a bit because all their day is centered around meal time. They get up, breakfast, chill until lunch, chill even longer until dinner…it's really centered around food and being able to eat. It's one of their favorite pastimes I'm sure, so being able to make that a more desirable and enjoyable time for them... [Room Number] was on hospice, and she was for a long time. She was degrading so much, and she didn't eat most of the time. Her mouth and lips were so dry and I'm sure she had just like no saliva to move stuff around and I felt like we did nothing for it. She didn't even have that thickening stuff, she didn't eat or drink anything for months. I feel [Director of Nursing] absolutely knew what was going on and she chose not to do anything about it."	"I would add more training to the actual nurse aide training. I mean it's not like that's a skill you have to check off on, at least in the Nebraska training, so I think that would be important, especially with a lot of nurse aides going to work in nursing homes, that's a big issue there, and you're not accurately trained [in aide training class] and then you're not accurately trained there either, then that's a big problem."

Discussion

- Common interview answers indicated little to no dysphagia training, apprehension and nervousness during feeding residents, heavy workloads, and overall need for more training and more aides.
- Suggestions:
  - Dysphagia-specific training would be a great addition to formal CNA and MA class training, as well as on-the-job orientation.
  - Quarterly, biannual, annual training
  - Residents would strongly benefit from increased staffing ratios. If increasing staffing is absolutely not possible, other changes should be implemented in effort to enhance residents' experiences.
  - Facilities could consider adding an aide at mealtimes only, or staggering mealtimes from floor to floor and having the extra aide work each floor's meals. Addition of specialists such as speech pathologists could also ensure residents' needs are met or exceeded.
  - Other countries have implemented volunteer programs for help feeding patients. This could immensely help aides while saving funds from facilities' tight finances.

Huang, C. S., Dutkowski, K., Fuller, A., & Walton, K. (2015). Evaluation of a pilot volunteer feeding assistance program: influences on the dietary intakes of elderly hospitalised patients and lessons learnt. The journal of nutrition, health & aging, 19(2), 206-210.

Discussion

In ten years, older adults will outnumber children for the first time in U.S. history. Aging baby boomers outnumber the expected number of geriatric caregivers, and these existent issues may only worsen as a result. Dysphagia is common among older adults and many chronic conditions, so dysphagia care will continue to gain prominence in nursing settings. Changes in the way residents with dysphagia are cared for have the potential to improve millions of lives.

Huang, C. S., Dutkowski, K., Fuller, A., & Walton, K. (2015). Evaluation of a pilot volunteer feeding assistance program: influences on the dietary intakes of elderly hospitalised patients and lessons learnt. The journal of nutrition, health & aging, 19(2), 206-210.

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Limitations

- Small sample size: 15
- Cannot generalize results onto general population
- Snowball sampling
  - Multiple participants from same workplace

Questions?

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References

Acreman, S. (2013). Nutrition in palliative care. British Journal of Community Nursing,14(10), 427-431. Retrieved November 26, 2018.

Allari, B. H. (2014). When the Ordinary Becomes Extraordinary: Food and Fluids at the End of Life. Generations,86-91. Retrieved November 26, 2018.

Data.census.gov, United States Census Bureau, 2018, data.census.gov/cedsci/table?q=65%2Band%2Bover&g=&hidePreview=false&table=S0103&tid=ACSST1Y2018.S0103&vintage=2018&lastDisplayedRow=23.

Brady, G. C., Roe, J. W., Brien, M. O., Boaz, A., & Shaw, C. (2017). An investigation of the prevalence of swallowing difficulties and impact on quality of life in patients with advanced lung cancer. Supportive Care in Cancer,26(2), 515-519. doi:10.1007/s00520-017-3858-6

Chiang, C. K., & Hwu, Y. J. (2018). Feeding experiences of nursing aides for residents with dysphagia. Geriatric Nursing, 39(4), 436-442.

Gillespie, L., & Raftery, A. (2014). Nutrition in palliative and end-of-life care. Nutrition and Palliative Care, S15-S20. Retrieved November 26, 2018.

Huang, C. S., Dutkowski, K., Fuller, A., & Walton, K. (2015). Evaluation of a pilot volunteer feeding assistance program: influences on the dietary intakes of elderly hospitalised patients and lessons learnt. The journal of nutrition, health & aging, 19(2), 206-210.

Marcolini, E. G., Putnam, A. T., & Aydin, A. (2018). History and Perspectives on Nutrition and Hydration at the End of Life. Yale Journal of Biology and Medicine,91(2), 173-176. Retrieved November 26, 2018, from https://www-ncbi-nlm-nih-gov.libproxy.unl.edu/pmc/articles/PMC6020733/.

Shune, S. E., & Linville, D. (2019). Understanding the dining experience of individuals with dysphagia living in care facilities: A grounded theory analysis. International journal of nursing studies, 92, 144-153.

References

Acreman, S. (2013). Nutrition in palliative care. *British Journal of Community Nursing,14*(10), 427-431. Retrieved November 26, 2018.

Allari, B. H. (2014). When the Ordinary Becomes Extraordinary: Food and Fluids at the End of Life. *Generations,*86-91. Retrieved November 26, 2018.

American Community Survey. "Population 65 Years and Over In The United States." Data.census.gov, United States Census Bureau, 2018, data.census.gov/cedsci/table?q=65%2Band%2Bover&g=&hidePreview=false&table=S0103&tid=ACSST1Y2018.S0103&vintage=2018&lastDisplayedRow=23.

Bell, C. L., Lee, A. S., & Tamura, B. K. (2015). Malnutrition in the nursing home. Current Opinion in Clinical Nutrition & Metabolic Care, 18(1), 17-23.

Blissett, K., Chima, V., & Lantz, M. S. (2018). From Stress to Serenity: The Use of Aromatherapy to Engage Patients in Care. *The American Journal of Geriatric Psychiatry, 26*(3), S119. doi:10.1016/j.jagp.2018.01.145

Blumberg, R., Feldman, C., Murray, D., Burnes, N., & Murawski, D. (2018). Food and Nutrition Care in Long-Term Care Facilities: Examining the Perspectives of Frontline Workers. Journal of nutrition in gerontology and geriatrics, 37(3-4), 145-157.

Brady, G. C., Roe, J. W., Brien, M. O., Boaz, A., & Shaw, C. (2017). An investigation of the

prevalence of swallowing difficulties and impact on quality of life in patients with advanced lung cancer. Supportive Care in Cancer,26(2), 515-519. doi:10.1007/s00520-017-3858-6

Carrier, N., West, G. E., & Ouellet, D. (2009). Dining experience, food services and staffing are associated with quality of life in elderly nursing home residents. JNHA-The Journal of Nutrition, Health and Aging, 13(6), 565-570.

Castellanos, V. H., Butler, E., Gluch, L., & Burke, B. (2004). Use of thickened liquids in skilled nursing facilities. Journal of the American Dietetic Association,104(8), 1222-1226. doi:10.1016/j.jada.2004.05.203

Chiang, C. K., & Hwu, Y. J. (2018). Feeding experiences of nursing aides for residents with dysphagia. Geriatric Nursing, 39(4), 436-442.

Garcia, J. M., & Chambers IV, E. (2010). Managing dysphagia through diet modifications. *AJN The American Journal of Nursing 110*(11), 26-33.

Geiger, J. L. (2017). The Safe and Effective Applications of Essential Oils in Alzheimer's Dementia. Arizona Geriatrics Society,1-9. Retrieved December 3, 2018.

Gibson, William E. “Age 65+ Adults Are Projected to Outnumber Children by 2030.” AARP, AARP, 14 Mar. 2018, www.aarp.org/home-family/friends-family/info-2018/census-baby-boomers-fd.html.

Gillespie, L., & Raftery, A. (2014). Nutrition in palliative and end-of-life care. Nutrition and Palliative Care, S15-S20. Retrieved November 26, 2018.

Holmes, S. (2010). Nutrition in the palliative care of chronic and life-threatening illness. British Journal of Community Nursing,15(Sup7). doi:10.12968/bjcn.2010.15.sup7.81209

Holmes, S. (2010). Withholding or withdrawing nutrition at the end of life. Nursing Standard,

25(14), 43-46. doi:10.7748/ns.25.14.43.s51

Huang, C. S., Dutkowski, K., Fuller, A., & Walton, K. (2015). Evaluation of a pilot volunteer feeding assistance program: influences on the dietary intakes of elderly hospitalised patients and lessons learnt. The journal of nutrition, health & aging, 19(2), 206-210.

Lee, I., Yang, Y., Ho, P. (2013). Chewing ability, nutritional status and quality of life. Journal of Oral Rehabilitation,41(2), 79-86. doi:10.1111/joor.12115

Marcolini, E. G., Putnam, A. T., & Aydin, A. (2018). History and Perspectives on Nutrition and Hydration at the End of Life. Yale Journal of Biology and Medicine,91(2), 173-176. Retrieved November 26, 2018, from https://www-ncbi-nlm-nih-gov.libproxy.unl.edu/pmc/articles/PMC6020733/.

Murray, J., Miller, M., Doeltgen, S., & Scholten, I. (2013). Intake of thickened liquids by hospitalized adults with dysphagia after stroke. International Journal of Speech-Language Pathology,16(5), 486-494. doi:10.3109/17549507.2013.830776

Payne, M., & Morley, J. E. (2018). Dysphagia, dementia and frailty.

Peladic, N. J., Orlandoni, P., Dell'Aquila, G., Carrieri, B., Eusebi, P., Landi, F., ... & Cherubini, A. (2019). Dysphagia in Nursing Home Residents: Management and Outcomes. *Journal of the American Medical Directors Association*, *20*(2), 147-151.

Shune, S. E., & Linville, D. (2019). Understanding the dining experience of individuals with dysphagia living in care facilities: A grounded theory analysis. International journal of nursing studies, 92, 144-153.

Teno, J. M., Mitchell, S. L., Skinner, J., Kuo, S., Fisher, E., Intrator, O., Mor, V. (2009).

Churning: The Association between Health Care Transitions and Feeding Tube Insertion

for Nursing Home Residents with Advanced Cognitive Impairment. *Journal of Palliative Medicine*,*12*(4), 359-362. doi:10.1089/jpm.2008.0168

Appendix

Demographic

1. How many years have you worked as a CNA/Medication Aide?

2. In what settings have you worked as a CNA/Medication Aide? I.e. hospital (wing?), skilled nursing, rehabilitation, assisted living, memory care, hospice.

3. Approximately what year did you receive your aide training?

Interview

"Difficulty swallowing (dysphagia) means it takes more time and effort to move food or liquid from your mouth to your stomach. Dysphagia may also be associated with pain. In some cases, swallowing may be impossible." (Mayo Clinic Staff, 2018).

4. Tell me about your experiences providing care to dysphagia patients.

5. How prepared did you feel upon beginning your job to feed dysphagia patients in a safe and dignified manner? Now?

6. Tell me about the training you received to feed/ care for dysphagia patients? Was it sufficient? If it is not sufficient, why not?

7. What is your biggest barrier for being able to provide the best care to patients with swallowing difficulties?

8. How do your regular tasks impact the care dysphagia patients receive? I.e. workload

Future Training

9. How can the barriers you described earlier be lessened or reduced?

10. In what ways do you learn best?

11. What sort of training/education would be of help to you in providing dysphagia care? For example, online courses, reading, video tutorials, role playing.

12. What differences would you like to see in regard to how patients with swallowing difficulties are cared for?

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University of Nebraska-Lincoln Institutional Review Board (IRB) 402-472-6965 irb@unl.edu	**FOR OFFICE USE ONLY** IRB #: 20190719563EX IRB Decision Date: Date Received: 06/16/2019 NUgrant Project ID: 19563 Form ID: 53085 Status: Certification of Exemption

The UNL Human Research Protection Program policies and procedures along with guidance documents and templates are available for your reference and use during the completion of this application.

- Only projects that meet the definition of research AND human subjects
- If your project does not require IRB approval, you are not required to submit this application; however, please be aware, IRB approval may not be granted if the research has already started or been conducted and the determination of IRB applicability was made incorrectly by the investigator.
- If your project does require IRB approval, the decision charts may not be used for exemption determinations, expedited review, or continuing review. Certain state laws and institutional policies, not taken into account within the decision charts, may affect review categories and applicability. Exemption determinations are required to be made by designated Human Research Protection Program staff members and are required to be submitted for official review and certification by completion of this application.

Contact the IRB at irb@unl.edu for further guidance.

Any general comments regarding this form can be added to the "Comments" button at the top of this page.

Basic Project Information

*** 1. Project Title:**

If this project corresponds with a current grant, contract, and/or award, use the same proposal title to allow for efficient communication between all necessary UNL offices including Research Compliance Services, the IRB and the Office of Sponsored Programs.

A Qualitative Analysis of the Barriers Faced by Nursing Assistants and Medication Aides in the Care of Dysphagia Patients

*** 2. Principal Investigator is:**

Undergraduate Student

*** Principal Investigator:**

Lauren Kreuzberg - lkreuzberg@nebraska.edu - 4024722178

*** Principal Investigator's Department**

Department of Gerontology

3. Secondary Investigator is:

Faculty

Secondary Investigator:

Julie Masters - jmasters@unomaha.edu - 4024720754

Secondary Investigator's Department

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Department of Gerontology

Description of Multi-Institutional Study Coordination

*** 4. Are external person(s) not affiliated as a faculty, staff or student with the University of Nebraska-Lincoln working on the project?**

No

*** 5. Is this a multi-institutional study? (i.e., colleagues from other institutions are on the research team)**

No

Project

*** 6. Will the project involve an external performance site other than the University of Nebraska-Lincoln where data collection will occur?**

No

*** 7. Does this project involve any international sites where the PI will either conduct or supervise the study?**

No

*** 8. The European Union's ('EU') General Data Protection Regulation ('GDPR'), regulates the processing by an individual, a company or an organization of personal data relating to individuals located (i.e., geographically and not to be confused with citizenship) in the EU. Will this project process/control any personal data, monitor the behavior of individuals, and/or offer good/services (paid or free) to or from someone who is located in an applicable country within the EU?**

No

The GDPR applies to persons located in the following countries Iceland, Liechtenstein, Norway, Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Italy, Ireland, Latvia, Lithuania, Luxembourg, Malta, the Netherlands, Poland, Portugal, Romania, Spain, Slovakia, Slovenia, Sweden and the United Kingdom. To learn more about the EU GDPR, including possible additional consent requirements, please visit the IRB Guidance webpage and reference the topic titled, European Union General Data Protection Regulation (EU GDPR).

*** 9. Does this project require review by Lincoln Public Schools (LPS)?**

No

*** 10. Describe the location(s) where recruitment and participation will take place (e.g., UNL, UNMC, UNO, UNK, at home, in a community building, schools, hospitals, clinics, prisons, unions, online, etc.).**

Lincoln area hospitals, skilled nursing facilities, and hospice facilities.

*** 11. Describe the facilities available to conduct the research (e.g., there will be a quiet room in the school to conduct interviews, a private research space, a participant will use their personal computer, etc).**

I will use a quiet private room at UNL or in the interviewee workplace for interviews.

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Funding

*** 12. Funding source:**

N/A

Project Dates

Note

The dates identified below are intended to be estimates of when the project will start and end and not when the application process begins.

*** 13. Project start date:**
(Start date is dependent upon approval)

06/10/2019

*** 14. Project end date:**

03/10/2020

Clinical Trials

The conduct of a clinical trial per any of the definitions below, requires certain language specific to the description of a clinical trial to be included in the consent form(s). Template language for this requirement can be found on the IRB website under the heading *ClinicalTrials.gov (CT.gov) Template Language.*

*** 15. Is this project a clinical investigation that is regulated by the Food and Drug Administration (FDA)?**

No

*** 16. Is this project a clinical trial that is funded or supported by a Federal Awarding Agency that follows the Common Rule at 45 CFR 46?**

No

*** 17. Is this project categorized as a clinical trial per the definitions provided by the National Institutes of Health (NIH)?**
(Note: The NIH definition is only applicable if your funding source is from the NIH.)

No

*** 18. Is this project categorized as a clinical trial per the definition provided by the International Committee of Medical Journal Editors (ICMJE) AND are you planning on submitting results of this project to journals that follow the ICMJE's recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals? A full list of journals that follow ICMJE recommendations is provided below. Please be aware some journals or sponsors may follow guidelines requiring ct.gov registration but are not listed. Please check with the specific journal or sponsor if you have questions regarding applicability of ct.gov registration.**

Journals Following the ICMJE Recommendations

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No

- Page 2 of the New Project Form is used to assign a preliminary review type (Exempt, Expedited or Full Board) upon submission to the IRB. Your selection of categories below will assist IRB staff in the assignment and initial review process. This assignment is only preliminary. IRB staff will also conduct an initial pre-review upon submission to confirm the most appropriate review type and applicable categories.
- Before completing this page there are a few items you might find helpful to know:
  - More than one category in the review type of Exempt and Expedited can be selected. The higher review level (i.e., Expedited) will be the default if this occurs.
  - Question marks appear throughout this page to assist you in making an informed decision about the category selection. Each question mark contains category specific information, general information, and intended use.
  - Review at an IRB meeting is only required if a project will be reviewed under the Full Board review category. The IRB meets at least monthly throughout the year. Be aware of submission deadlines.
  - Exempt and Expedited projects are reviewed on an ongoing basis with no submission deadline requirements.
  - If there questions about any of the categories or review types, please contact the IRB at irb@unl.edu or 402-472-6965 or visit our website at https://research.unl.edu/researchcompliance/human-subjects-research/.

Full Board Category

Any categories selected at the proposal stage are only preliminary. The IRB Coordinator will confirm the appropriate review type and respective category upon initial review with final decision authority reserved by the IRB.

*** Is this project greater than minimal risk?**

No

*** Will the project involve prisoners?**

No

Exempt Category

Any categories selected at the proposal stage are only preliminary. The IRB Coordinator will confirm the appropriate review type and respective category upon initial review with final decision authority reserved by the IRB.

☐ **Exempt Category 1: Research conducted in established or commonly accepted educational settings that specifically involves normal educational practices that are not likely to adversely impact students' opportunity to learn required educational content or the assessment of educators who provide instruction. This includes most research on regular and special education instructional strategies, and research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.**

☒ **Exempt Category 2: Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:**

☒ **(2a) The information obtained is recorded by the investigator in such a manner that the identity of the human participants cannot readily be ascertained, directly or through identifiers linked to the participants; or**

- ☐ **(2b) Any disclosure of the human participants' responses outside the research would not reasonably place the participants at risk of criminal or civil liability or be damaging to the participants' financial standing, employability, educational advancement, or reputation; or**

- ☐ **(2c) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by §46.111(a)(7).**

☐ **Exempt Category 3: Research involving benign behavioral interventions in conjunction with the collection of information from an adult (19 or older in the State of Nebraska) subject through verbal or written responses (including data entry) or audiovisual recording if the subject prospectively agrees to the intervention and information collection and at least one of the following criteria is met:**

- ☐ **(3a) The information obtained is recorded by the investigator in such a manner that the identity of the human participants cannot readily be ascertained, directly or through identifiers linked to the subjects; or**

- ☐ **(3b) Any disclosure of the human participants' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the participants' financial standing, employability, educational advancement, or reputation; or**

- ☐ **(3c) The information obtained is recorded by the investigator in such a manner that the identity of the human participants can readily be ascertained, directly or through identifiers linked to the participants, and an IRB conducts a limited IRB review to make the determination required by §46.111(a)(7).**

Regulatory Requirements for use of this category (3) and any of the criteria:
For the purposes of this category, benign behavioral interventions are brief in duration, harmless, painless, not physically invasive, not likely to have a significant adverse lasting impact on the subjects, and the investigator has no reason to think the subjects will find the interventions offensive or embarrassing. Provided all such criteria are met, examples of such benign behavioral interventions would include having the subjects play an online game, having them solve puzzles under various noise conditions, or having them decide how to allocate a nominal amount of received cash between themselves and someone else.

If the research involves deceiving the subjects regarding the nature or purposes of the research, this exemption is not applicable unless the subject authorizes the deception through a prospective agreement to participate in research in circumstances in which the subject is informed that he or she will be unaware of or misled regarding the nature or purposes of the research.

☐ **Exempt Category 4: Secondary research for which consent is not required: Secondary research uses of identifiable private information or identifiable biospecimens, if at least one of the following criteria are met:**

- ☐ **(4a) The identifiable private information or identifiable biospecimens are publicly available; or**

- **(4b) Information, which may include information about biospecimens, is recorded by the investigator in such a manner that the identity of the human participants cannot readily be ascertained directly or through identifiers linked to the participants, the investigator does not contact the participants, and the investigator will not re-identify participants; or**

- **(4c) The research involves only information collection and analysis involving the investigator's use of identifiable health information when that use is regulated under the Health Insurance Portability and Accountability Act (HIPAA) at 45 CFR parts 160 and 164, subparts A and E, for the purposes of health care options or research as those terms are defined at 45 CFR 164.501 or for public health activities and purposes as described under 45 CFR 164.512(b); or**

- **(4d) The research is conducted by, or on behalf of, a Federal department or agency using government-generated or government-collected information obtained for nonresearch activities, if the research generates identifiable private information that is nor will be maintained on information technology that is subject to and in compliance with section 208(b) of the E-Government Act of 2002, 44 U.S.C. 3501 note, if all of the identifiable private information collected, used, or generated as part of the activity will be maintained in systems or records subject to the Privacy Act of 1974, 5 U.S.C. 552a, and, if applicable, the information used in the research was collected subject to the Paperwork Reduction Act of 1995, 44 U.S.C. 3501 et seq.**

- **Exempt Category 5: Research and demonstration projects which are conducted or supported by a Federal department or agency, or otherwise subject to approval of department or agency heads (or the approval of the heads of bureaus or other subordinate agencies that have been delegated authority to conduct the research and demonstration projects), and that are designed to study, evaluate, improve, or otherwise examine public benefit or service programs, including procedures for obtaining benefits or services under those programs, possible changes in or alternatives to those programs or procedures, possible changes in methods or levels of payment for benefits or services under those programs. Such projects include, but are not limited to, internal studies by Federal employees, and studies under contracts or consulting arrangements, cooperative agreements, or grants. Exempt projects also include waivers of otherwise mandatory requirements using authorities such as sections 1115 and 1115A of the Social Security Act, as amended.**

  Regulatory Requirements for use of this category (5):
  Each Federal department or agency conducting or supporting the research and demonstration projects must establish, on a publicly accessible Federal website or in such other manner as the department or agency head may determine, a list of the research and demonstration projects that the Federal department or agency conducts or supports under this provision. The research or demonstration project must be published on this list prior to commencing the research involving human subjects.

- **Exempt Category 6: Taste and food quality evaluation and consumer acceptance studies if wholesome foods without additives are consumed, or if a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the Food and Drug Administration, or approved by the Environmental Protection Agency or the Food Safety and Inspection Service of the U.S. Department of Agriculture.**

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Note
The following Exempt categories 7 & 8 would allow the storage, maintenance and/or use of identifiable private information and/or biospecimens if broad consent was used. The current categories are included in the application to gauge the interest of the UNL research community in implementing the use of broad consent under the Exempt categories.

At this time, it is the intention of the UNL IRB to potentially offer these Exemptions in the future as a way to reduce regulatory burden for investigators; however, there is also a considerable amount of work to be done to be able to ensure that the exemptions are implemented in a manner that meets all regulatory requirements, including the tracking of all non-consent for all projects using Exempt categories 7 & 8 at the institutional level. Although, the UNL IRB will not be approving the use of broad consent at this time under the Exempt categories, all previous regulatory requirements through traditional informed consent for non-exempt (i.e., Expedited or Full Board) storage, maintenance, and research use involving identifiable information and biospecimens are still available.

- ☐ **Exempt Category 7: Storage or maintenance for secondary research for which broad consent is required: Storage or maintenance of identifiable private information or identifiable biospecimens for potential secondary research use if an IRB conducts a limited IRB review and makes the determinations required by §46.111(a)(8).**

- ☐ **Exempt Category 8: Secondary research for which broad consent is required: Research involving the use of identifiable private information or identifiable biospecimens for secondary research use, if all of the following criteria are met:**

  - ☐ **(8a) Broad consent for the storage, maintenance, and secondary research use of identifiable private information or identifiable biospecimens was obtained in accordance with 45 CFR 46.111(a)(8); and the reviewer conducts a limited IRB review and makes the determination in accordance with 45 CFR 46.111(a)(7); and the reviewer makes the determination that the research to be conducted is within the scope of broad consent; the return of individual research results to subjects is not part of the study plan (this provision does not prevent an investigator from abiding by any legal requirements to return individual research results); and documentation of informed consent was obtained in accordance with 45 CFR 46.117.**

  - ☐ **(8b) Waiver of documentation of consent was obtained in accordance with 45 CFR 46.117.**

Expedited Category

Any categories selected at the proposal stage are only preliminary. The IRB Coordinator will confirm the appropriate review type and respective category upon initial review with final decision authority reserved by the IRB.

- ☐ **Expedited Category 1: Clinical studies of drugs and medical devices only when one of the two conditions is met:**

  - ☐ **Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required.**

  - ☐ **Research on medical devices for which (i) an investigational device exemption**

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application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.

- ☐ **Expedited Category 2: Collection of blood sample by finger stick, heel stick, ear stick, or venipuncture as follows:**
  - ☐ **From healthy, non-pregnant adults who weigh at least 110 pounds. In studies in which more than 400 ml of blood is to be drawn within an 8 week period, the participant must have a baseline hemoglobin level of 12.0 grams. After 250 ml of blood has been drawn, the hemoglobin level must be retested; anyone whose hemoglobin has fallen below 11.0 grams must be withdrawn from the study; or**
  - ☐ **From other adults and children, considering the age, weight, and health of the participants, the collection procedure, the amount of blood to be collected and the frequency with which it will be collected. For these participants, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times (or research sessions) per week.**
- ☐ **Expedited Category 3: Prospective collection of biological specimens for research purposes by non-invasive means.**
- ☐ **Expedited Category 4: Collection of data through non-invasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice (excluding procedures involving x-rays or microwaves). Where medical devices are employed, they must be cleared or approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications.)**
- ☐ **Expedited Category 5: Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis).**
- ☐ **Expedited Category 6: Collection of data from voice, video, digital, or image recordings made for research purposes.**
- ☐ **Expedited Category 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.**

Description of Participants

* 1. Estimate the number of participants per category via the table provided:

	Male	Female	Unspecified	Totals

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Adults	3	12		15
Children				0
Totals	3	12	0	15

* 2. Please indicate all special groups who will be **purposefully** recruited for the project. Please check all that apply.

- ☒ **Adults, non students**
- ☐ **UNL Students**
- ☐ **Students attending external institutions (i.e., not UNL)**
- ☐ **Children (under age 19)**
- ☐ **Persons who are institutionalized**
- ☐ **Prisoners**
- ☐ **Pregnant women/fetuses/neonates**
- ☐ **Persons who are experiencing restricted or inequitable civil rights (including parolees and LGBT people in certain states)**
- ☐ **Persons with HIV/AIDS**
- ☐ **Adults and/or children with legal representatives**
- ☐ **Other**
- ☐ **Employees**
- ☐ **Persons currently serving in the military**
- ☐ **Veterans**
- ☐ **Persons with language impairment(s)**
- ☐ **Persons with mental disabilities**
- ☐ **Persons with physical disabilities**
- ☐ **Persons with psychological impairment**
- ☐ **Persons who are decisionally-impaired**
- ☐ **Persons with neurological impairment**
- ☐ **Wards of the state**

Inclusion Criteria

* **3. Will both male and female participants be recruited?**

Yes

* **4. Will participation be limited to certain racial or ethnic groups?**

No

* **5. Describe the inclusion criteria that will be followed to select the participants to be enrolled in the research, including the lower and upper age range of participants. If the project will include various stages of recruitment, please describe the selection or inclusion criteria for each phase.**

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Participants will include certified nursing assistants and medication aides over the age of 19.

Note

Nebraska age of majority is 19 years of age, with exceptions. If any participants below the age of 19 years will be included in the research, additional requirements may be necessary based on the inclusion of minors, the research review level and the category in which the project will be reviewed under.

*** 6. Describe the process that will be followed to screen and determine the participant's eligibility. For example, eligibility determinations could be completed through a participant self-determination process, screening questions included in a survey, pre-screening interview questions, or through access of private information or biospecimens.**

Using a snowball sampling technique, I will contact certified nursing assistants (CNAs) and medication aides that I know to find willing participants. I will avoid those who I know personally to avoid bias. I will look up their names on the Nebraska Department of Health and Human Services certifications list website that is available to the public to ensure they are state registered CNAs or medication aides.

*** 7. Describe your access to the population that will allow recruitment of the necessary number of participants. For example, if you are an employee of an organization that will allow for the research to occur, are the instructor of the classroom in which the research will take place, or you have a professional/personal relationship with someone in the targeted population, etc., describe that in your response.**

I have worked in a skilled nursing/rehabilitation facility and an assisted living facility and know many people from my jobs and classes who work as CNAs or medication aides. I will use their contacts to add to the number of possible participants to recruit.

*** 8. Describe the process that will be followed, facilities available, or locations that will be used during the conduct of research to protect the privacy of participants, if applicable. In this question, privacy refers to procedures such as how a participant will complete a sensitive research questionnaire in private without having the possibility of someone reading their responses over their shoulder or possibly having someone overhear responses during an interview.**

Data collection will occur via interviews in closed rooms. Participant names will not be associated or said with their responses. All data will be secured in a password protected folder on my laptop. Paper copies will be secured in my advisor Dr. Master's locked cabinet. Data will be destroyed once analyzed by being deleted and then deleted from my online trash bin. Paper copies will be shredded after three years. Name of participant workplace will not be associated with their answers, only type of facility, i.e. hospital, hospice facility, skilled nursing facility.

Exclusion Criteria

*** 9. If not already described above, will any groups or categories of participants be excluded from the project?**

No

*** 10. Specifically, will females of child-bearing potential or pregnant females be excluded?**

No

*** 11. Will subjects be vulnerable to coercion or undue influence? This question must be answered as yes, if a member of the research team or an immediate family member are in or perceived to be in a position of authority over potential participants. For example, this may be a boss/director of an organization, or the instructor of classroom in which research takes place.**

No

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Research Methodology and Data Sources

*** 1. Will the project involve audio recording?**

Yes

*** 1.a. What will be recorded? How long will the recordings be stored? How will they be stored? Where will they be stored? Who will have access to the recordings? When will the recordings be destroyed? How will the recordings be destroyed?**

The interviews with research participants will be audio recorded. The recordings will be stored on my password protected laptop in a password protected folder until the data is reviewed and collected, then I will delete the recordings. I will be the only one with access to the audio recordings. Once deleted, I will also delete from the trash bin on my laptop.

*** 1.b. Will the audio recordings be transcribed?**

Yes

*** 1.b.1. How will the audio and transcripts be transferred between the research team and the transcriptionist or transcription services organization? Will the audio and/or transcripts contain identifying information? Who is completing the transcription? If being completed by an online service, what protocols are in place to ensure data security? As a recommendation, transcriptionists external to the research team should complete a confidentiality agreement.**

Note

Depending on the sensitivity of the data and the vulnerability of the participants, additional requirements for transcription services may be necessary. A template confidentiality agreement is available on the IRB website.

I will transcribe recordings to identify themes from their experiences. I will keep these transcriptions in a locked folder on my password protected laptop. Names will not be associated with transcriptions. I will instruct participants to not say their name on the recording.

*** 2. Will information be obtained from study participant(s) utilizing web, mobile or online data transmission procedures? For example, this question would be answered "yes" if the project involves the use of Qualtrics as an online survey provider or a mobile application.**

No

*** 3. Will the project obtain, use, study, or analyze Protected Health Information (PHI) (i.e., information obtained from or provided to a covered entity or business associate such as a doctor's office, hospital, nursing home, insurance company, etc.)? If this project uses PHI, training is required to be completed by PIs, Supervising Investigators and participating personnel who conduct research applicable to the Health Insurance Portability and Accountability Act (HIPAA). *Information Privacy and Security – Information for Researchers: Basic Course* is completed through the Collaborative Institutional Training Initiative (CITI).**

Note

Self-reported health information provided directly to the investigator is not covered by the Privacy Rule if that investigator is not part of the workforce of a covered entity.

No

*** 4. Will the project ask questions about illegal drug use or criminal activity that could place participants at risk for legal action?**

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No

*** 5. Does a Certificate of Confidentiality apply to this project?**

Note

Certificates of Confidentiality are obtained from federal agencies, such as the National Institutes of Health or the Department of Justice.
Learn more about Certificates of Confidentiality on the UNL IRB webpage. If a project involves a Certificate of Confidentiality, specific information must be present in the consent form informing participants of the certificate. See the IRB website for more information.

No

*** 6. Will the project involve photography?**

No

*** 7. Will the project involve videography?**

No

*** 8. Will the project use, or analyze archival or secondary data?**

No

*** 9. Will the project collect, use, study, analyze, or generate bio-specimens such as cells, tissues, saliva, blood, serum, human excreta, tissue, hair, teeth, etc.?**

No

*** 10. Will this project store, maintain, use or generate identifiable private biospecimens or information, including participant contact information, for the purposes of future use by the study team or others outside of the study team? Typically information or biospecimens for future use are stored in a biorepository, data repository or registry.**

Note

Biospecimens or information are considered identifiable if identifier(s) are readily accessible to at least one member of the study team, including a master list linking names and codes.

No

*** 11. Does this project utilize human embryonic stem cells (hESC) and/or their derivatives?**

No

*** 12. Does this project utilize human fetal cells, fetal tissue (hFT) and/or their derivatives?**

No

*** 13. Does this project involve the use of ionizing radiation or ionizing radiation-emitting device(s) that is not part of a clinical patient's standard of care?**

Note

A magnetic-resonance imaging (MRI) machine does not emit ionizing radiation.

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No

*** 14. Will the project ask participants to perform physical tasks (e.g. climbing a ladder, doing a push-up, contracting a muscle, running on a treadmill, etc.)?**

No

*** 15. Does this project involve a medical device and it is the object of the investigation?**

Note

Even some smartphone applications could be regulated by the FDA if they meet the definition of a medical device. Always consult with your IRB coordinator if you are unsure how to answer this question. Be aware, all projects regulated by the FDA are referred to the UNMC IRB for review under the FDA regulations.

No

*** 16. Does this project involve a FDA-approved and marketed device and it is NOT the object of the investigation?**

No

Purpose, Methods & Procedures

1. Indicate the project's design by checking the appropriate box(es):

☐	**Action research**	☐	**Case-control**
☐	**Class Project**	☐	**Cohort**
☐	**Correlational**	☐	**Cross-sectional**
☐	**Ethnography**	☒	**Exploratory**
☐	**Evaluation**	☐	**Intervention**
☐	**Longitudinal**	☐	**Pilot**
☐	**Randomized**	☐	**Other**

*** 2. What is the significance/purpose of the project? (Provide a brief description in lay terms including a brief literature justification and objectives/aims of the research.)**

Dysphagia is a common symptom of various different prevalent diseases. When someone loses the ability to swallow regularly, their value does not decline. It is imperative to work to enhance or maintain dignity, self-worth, and life satisfaction of dysphagia patients receiving artificial nutrition and hydration. By 2030, 1 in 5 Americans will be of retirement age, making it is essential that this problem is addressed and dysphagia care is given the education and training that patients deserve. (US Census Bureau, 2018). When thinking of skilled nursing facilities, meal times may be close to the only time that residents socialize with someone not on the care team. It is often difficult to get residents engaged in activities or to transport them to the social events offered with the staff scheduled (Allari, 2014). As suggested by Murray et al., Offering a greater amount of thickened liquids at mealtimes, when nursing staff are more available to assist individuals, may improve intake (2013). If residents are left to consume thickened liquids at snack times or on their own, they are considerably less likely to drink the liquid and therefore become dehydrated (Murray et al., 2013). While thickened liquids are a good idea with great intentions, it often leads to dehydration as consumption is not adequately encouraged, monitored, assisted, and provided. In order for this to work, it needs to be provided and encouraged to maintain sufficient hydration and avoid the next step of tube feeding. Certified nursing assistants and medication aides are the frontline workers in facilities where dysphagia care is taking place, so interviewing them will give us significant information on the barriers to providing high quality, dignified care.

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Allari, B. H. (2014). When the Ordinary Becomes Extraordinary: Food and Fluids at the End of Life. Generations,86-91. Retrieved November 26, 2018.

Marcolini, E. G., Putnam, A. T., & Aydin, A. (2018). History and Perspectives on Nutrition and Hydration at the End of Life. Yale Journal of Biology and Medicine,91(2), 173-176. Retrieved November 26, 2018, from https://www-ncbi-nlm-nih-gov.libproxy.unl.edu/pmc/articles/PMC6020733/.

US Census Bureau. Older People Projected to Outnumber Children. The United States Census Bureau, United States of America Federal Government, 3 Dec. 2018, www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html.

*** 3. Describe the data collection procedures sequentially. (Upload all interview questions, measurements, images, examples, etc. on page nine. Do not just provide a list of procedures, but rather this section must include enough information for the IRB to understand what the participants will be asked to complete.)**

Participants will be asked to take part in an interview regarding their education and training on dysphagia care and their firsthand experiences. They will be asked to identify barriers to providing high quality dysphagia care and how they believe these barriers can be reduced, including preferences of type of future training. Participants will be provided interview questions in advance. Interviews will be conducted in a quiet, closed room at UNL or at the participants' workplaces. Interviews will be recorded using an audio recorder. Files will be uploaded from the recorder onto a locked folder on my password protected laptop. Once the recordings have been analyzed, I will delete the files from the folder and the trash bin.

*** 4. Briefly describe the data analysis plan.**

I will use a qualitative analysis to identify themes in barriers to providing dysphagia care. I will use a thematic analysis to identify these barriers once the interviews have been conducted. I will use descriptive statistics to show the demographics of the sample.

*** 5. Does this project involve deception?**

No

*** 6. Describe how long, in terms of time, the procedures will take a participant to complete. The description should include the duration of a session, the number of sessions, over what period of time and the total time required to complete the procedures.**

Each participant will take part in one interview. Each interview is expected to take 25-35 minutes to complete.

*** 7. Will there be any follow-up with the participant or will reminders be sent to the participant?**

Yes

*** 7.a. Describe how the follow-up/reminder(s) will be completed (e.g. in-person, email, text-message, etc.). Describe the number of follow-up/reminder(s) that will be completed. (Upload all applicable scripts, templates, email, etc. on page nine.)**

I will send one email reminder to the participant 2-3 days before the scheduled interview.

*** 8. Describe any procedure not being done solely to achieve the project's proposed purpose. For example, a student will always complete the assignment described in the procedures during their classtime but the survey evaluating the assignment is done strictly for the project.**

N/A

*** 9. Describe the research team's available time allocated to conduct and complete the project. Essentially, the IRB would like to know if your time available would be sufficient to achieve the results successfully in a responsible manner.**

The research will be conducted through the remainder of the summer 2019 semester and into the fall 2019. This way, there is enough time to reach out to people I know, find possible participants they know, secure participants, set up interview times, and conduct the interviews.

*** 10. Describe the process followed to ensure that all persons assisting with the research (e.g. data collectors, transcriptionists, research assistants, etc.) are adequately trained, have the qualifications and appropriate training to perform the procedures included in the research. Describe the communication plan that the research team will follow to ensure that all personnel members , are informed about the protocol, any changes to the protocol, research-related duties and functions, etc.**

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I have completed the CITI training and will be working closely with CITI certified Dr. Masters to ensure proper guidelines and procedures are being followed.

Recruiting Procedures

*** 1. Describe how potential participant names and contact information will be obtained. For example, a list of names will be obtained from the telephone directory.**

I will be reaching out to certified nursing assistants and medication aides using a snowball sampling technique. I will get participants' contact information from CNAs and medication aides who I know. They will refer possible participants to me, including their contact information.

*** 2. Describe how potential participants will be approached or told about the opportunity to participate in the project. Ensure all phases of recruitment are described. Upload all applicable recruitment documents such as scripts, flyers, templates, etc. on page nine.**

An email will be sent to the participants I am trying to recruit with information on the purpose and content of the project. They will be asked to participate in an interview about their training, experiences, barriers, and training preferences concerning dysphagia care. If they are interested in participating, I will set up an interview time and location. I will send a reminder email 2-3 days before the interview.

Benefits and Risks

*** 3. Describe any direct benefits to participants, if any.**

Note:

Payments or incentives (including credit) should be discussed in section 6.9.a.

There are no direct benefits.

*** 4. Will any individual results of the research or procedures/tests completed, be provided back to the participant?**

No

*** 5. Describe the benefits of the research to society, if any.**

A societal benefit of this research is to identify barriers in dysphagia care. This can help identify gaps in training, education, continuing training, and ways to enhance the quality of care residents of hospitals, skilled nursing facilities, and hospice facilities.

*** 6. Describe all risks to the participant including a breach of confidentiality, if applicable. What will be done to minimize the risk(s)? If there are no known risks, this should be stated.**

N/A

*** 7. Does this research involve procedures, equipment or tests that could reasonably result in an incidental finding?**

No

*** 8. Describe the availability of medical or psychological resources that participants might require as a consequence of the research and/or in the case of incidental findings, if applicable.**

N/A

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Compensation/Incentives and/or Cost for Participation

*** 9. Will compensation or incentives (including money, gift certificates, extra credit, books, t-shirts, etc.) be provided to participants?**

No

*** 10. Will the research require the participant to pay for any aspects of the study or cost for participation, including cost for travel and transport to and from the study site?**

No

Informed Consent Process

*** 1. Describe how informed consent/assent will be obtained and the process that will be followed to ensure the participant understands the information presented. (Upload age appropriate consent/assent forms, if applicable, on page nine.)**

I will obtain informed consent by explaining the confidentiality procedures and the process of the interview. I will explain that participants may opt out at any time or refuse to answer any question. I will explain the use of their responses in my project and all participants will sign a consent form before the interview begins. I will instruct participants to not say their name on the audio recording.

*** 2. Describe the person(s) who will obtain participant consent/assent.**

The primary investigator will obtain written consent before beginning the interviews.

*** 3. Describe who will provide consent/assent. If you have identified the inclusion of either child or adult wards or persons with a legally authorized representative (LAR) within section 3.2 of the protocol, describe the process that will be followed to ensure the LAR is providing the consent for the participant.**

The CNA/Medication Aide participant will provide written consent before the interview. All interviewees will be age 19+.

*** 4. Describe the waiting period, if any, between when the potential participant will be informed of the study and when consent will be obtained. If multiple data collection points are included within the project, describe the amount of time between each period.**

There will be a waiting period between a few days to a few weeks depending on our shared availability to schedule the interview. The participant will give consent before the interview starts at the meeting time for the interview.

*** 5. Describe the primary language that will be used by those obtaining consent.**

English

*** 6. Describe the primary language understood by the participant. If translation services (verbal and/or written) are needed, please describe that here. If written materials are necessary a Translation Certification Form is required.**

English

*** 7. Will any subjects be decisionally impaired so that they do not have the capacity to give consent?**

No

*** 8. In certain cases involving non-exempt research (i.e. Expedited or Full Board), a waiver of informed consent or a waiver of an element of informed consent may be requested. Additionally, for projects including UNL students who are 17 or 18 years of age, a waiver of parental consent may be requested. Would you like to request a waiver of consent or a waiver of a consent element?**

No

9. In certain cases involving non-exempt research (i.e., Expedited or Full Board), a waiver of informed consent documentation may be

requested. Electronic consent may be a typical process where consent documentation might be waived.

Note

In the state of Nebraska, electronic signature must be individually identifiable to the person signing to constitute electronic signature.

*** Will this project request to waive consent documentation (e.g. signature)?**

No

Note

Consent documentation cannot be waived when an authorization to access Protected Health Information is required under the HIPAA regulations.

Confidentiality

*** 1. The project should make adequate provisions to maintain the confidentiality of the data. Describe how confidentiality of all records will be maintained.**

No identifying characteristics or names of the participants or workplaces will be included in the analysis, write up, and finished product. No names or identifying characteristics will be included in the research or thesis, and any information including their name, such as consent forms, will be locked in a password protected laptop. The signed informed consent forms will be secured in a locked cabinet in Dr. Master's single office in Nebraska Hall. Data/research records will be maintained for at least three years following the completion of the research. Paper copies will be shredded after 3 years.

*** 2. Will participants be identifiable during data collection or in the results? (This question should be answered "yes" if data collection is completed in an in-person setting or if data will be coded throughout the research process and a link is maintained between the code and participant identifiers.)**

Yes

*** 2.a. Describe how participants will be identified during the data collection procedures and in the data.**

Participants will be described using descriptive statistics. Noted characteristics will include gender, years experience, and occupation.

*** 2.b. If the data are coded, describe if a list linking names and codes will be used. The description should include the process that will be followed to keep the list secure during and after data collection and when the list will be destroyed. If the list will continue to be stored after all data collection procedures are complete and data has been verified, a justification for long-term storage must be provided.**

N/A

*** 3. Describe how long the project records and data will be kept. The description should differentiate between the length of storage time for identifiable and de-identified records, if applicable.**

The recordings will be kept until they are reviewed and the data is recorded. Then I will delete the data from my password protected laptop and password protected thesis folder.

*** 4. Describe where and how records and data collected will be stored. The description should include how both electronic and/or paper/physical records and data will be stored. Specificity regarding secure UNL servers vs. external servers possibly utilizing cloud computing must be**

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provided, if applicable.

The digital files will be stored on my password protected laptop in a designated, password protected folder. Research records and data will be maintained for at least three years after the completion of research.

*** 5. Describe all persons or entities planning to have access to the records and/or data.**

Only the principal and secondary investigators will have access to the recordings and data.

*** 6. Describe how data and/or research results will be reported. The description should include whether the data will be reported individually, identifiable, or in summary (aggregate) format. This description should also consider the possibility of deductive disclosure when reporting results or describing the research in a manuscript. If applicable, describe if masking procedures or certain descriptions would or would not be used. Also, describe if the data/results will be reported at conferences, in journals, in a thesis, in a dissertation, to the funding agency, back to the project site, etc.**

The data will be presented in a summary format with no identifiers of the participants. No names or workplaces will be included. The results will be reported in an undergraduate thesis.

Data Monitoring & Sharing

*** 7. Does the project require data safety monitoring?**

No

*** 8. Do you plan to share the data collected during this project through public-use files, repositories or other means outside of your approved research team and/or sites?**

Yes

*** 8.a. Do you have an established data sharing plan?**

No

*** 8.b. Please describe the process in which data will be shared. For example, data will be stored in a repository such as the UNL Data Repository (UNLDR) through UNL Libraries; or, data will be made available to colleagues via Box in a de-identified folder. (These are only examples to illustrate possible answers. Please provide as much detail as possible when describing the data sharing process.)**

I plan to share my final thesis with the UNL Honors Program. I will share it for approval for graduation with honors and plan to allow them to share the thesis in the undergraduate thesis library, where undergraduate students can go to read past theses for inspiration.

*** 8.c. Will all data be de-identified when shared? De-identified means the data does not contain information that would link a participant's identity with the data collected including the ID code if the master list still exists.**

Yes

*** 8.c.i. Describe the methods that will be used to ensure proper de-identification of all data. Please be cognizant of small sample sizes and how this may affect the possibilities of re-identification of a research participant.**

No names, identifiers, or workplace names will be included in the thesis. The only information about the participants that will be public is the occupation, gender, and years of experience. This will not allow anyone to identify the participants since the data about them is so general.

Note

Information about data sharing must be consistently described to the research participant within the

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consent form.

Questionnaires, Surveys, and Testing Instruments

*** Please list all questionnaires, surveys, and/or assessment instruments/measures used in the project.**

Demographic
1. How many years have you worked as a CNA/Medication Aide?
2. In what settings have you worked as a CNA/Medication Aide? I.e. hospital (wing?), skilled nursing, rehabilitation, assisted living, memory care, hospice.
3. Approximately what year did you receive your aide training?

Interview
"Difficulty swallowing (dysphagia) means it takes more time and effort to move food or liquid from your mouth to your stomach. Dysphagia may also be associated with pain. In some cases, swallowing may be impossible." (Mayo Clinic Staff, 2018).

4. Tell me about your experiences providing care to dysphagia patients.
5. How prepared did you feel upon beginning your job to feed dysphagia patients in a safe and dignified manner? Now?
6. Tell me about the training you received to feed/ care for dysphagia patients? Was it sufficient? If it is not sufficient, why not?
7. What is your biggest barrier for being able to provide the best care to patients with swallowing difficulties?
8. How do your regular tasks impact the care dysphagia patients receive?

Future Training
9. How can the barriers you described earlier be lessened or reduced?
10. In what ways do you learn best?
11. What sort of training/education would be of help to you in providing dysphagia care? For example online courses, reading, video tutorials, role playing.
12. What differences would you like to see in regard to how patients with swallowing difficulties are cared for?

Uploaded Attachments

Please submit copies of the following:

- **Funding application**
- **Institutional Approval letters**
- **Data sharing plans**
- **Recruitment flyers, ads, phone scripts, emails, etc.**
- **Informed Consent Forms, emails, and/or letters**
- **If transcriptions are required, Confidentiality Agreement that transcriptionists will sign**
- **If this is a study utilizing PHI, Release of Authorization that will be used to obtain permission from the participant for the agency/institution to release protected health information for project purposes or a letter from the agency/institution documenting agreement to provide protected health information for project purposes**
- **All Instruments/Measures used in the project**

Please upload all documents that would include the IRB approval stamp as a PDF. These documents could include recruitment materials AND informed consent/assent forms.

☒Email Reminder.docx
☒Email Invitation (1).docx
☒Informed Consent.docx

University of Nebraska Lincoln

Official Approval Letter for IRB project #19563 - New Project Form

July 17, 2019

Lauren Kreuzberg
Department of Gerontology
LLN 132B UNL NE 68588

Julie Masters
Department of Gerontology
NH 310 UNL NE 685880562

IRB Number: 20190719563EX
Project ID: 19563
Project Title: A Qualitative Analysis of the Barriers Faced by Nursing Assistants and Medication Aides in the Care of Dysphagia Patients

Dear Lauren:

This letter is to officially notify you of the certification of exemption of your project for the Protection of Human Subjects. Your proposal is in compliance with this institution's Federal Wide Assurance 00002258 and the DHHS Regulations for the Protection of Human Subjects at 45 CFR 46 2018 Requirements and has been classified as exempt. Exempt categories are listed within HRPP Policy #4.001: Exempt Research available at: http://research.unl.edu/researchcompliance/policies-procedures/.

o Date of Final Exemption: 07/17/2019
o Review conducted using exempt category 2b at 45 CFR 46.104
o Funding (Grant congruency, OSP Project/Form ID and Funding Sponsor Award Number, if applicable): N/A

You are authorized to implement this study as of the Date of Final Approval: 07/17/2019.

We wish to remind you that the principal investigator is responsible for reporting to this Board any of the following events within 48 hours of the event:
* Any serious event (including on-site and off-site adverse events, injuries, side effects, deaths, or other problems) which in the opinion of the local investigator was unanticipated, involved risk to subjects or others, and was possibly related to the research procedures;
* Any serious accidental or unintentional change to the IRB-approved protocol that involves risk or has the potential to recur;
* Any protocol violation or protocol deviation
* An incarceration of a research participant in a protocol that was not approved to include prisoners
* Any knowledge of adverse audits or enforcement actions required by Sponsors
* Any publication in the literature, safety monitoring report, interim result or other finding that indicates an unexpected change to the risk/benefit ratio of the research;
* Any breach in confidentiality or compromise in data privacy related to the subject or others; or
* Any complaint of a subject that indicates an unanticipated risk or that cannot be resolved by the research staff.

This project should be conducted in full accordance with all applicable sections of the IRB Guidelines and you should notify the IRB immediately of any proposed changes that may affect the exempt status of your research project. You should report any unanticipated problems involving risks to the participants or others to the Board.

If you have any questions, please contact the IRB office at 402-472-6965.

Sincerely,

Rachel Wenzl, CIP
for the IRB

Full Accreditation